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TITLE: Effects of Alternative Decision Support Technologies on Breast Cancer Patients' Knowledge of Options and Satisfaction with Treatment Decisions

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13. ABSTRACT (Maximum 200 words) The objectives of the research are to (1) develop an innovative computer-based decision support system (CDSS) that will enable women with breast cancer to integrate the information available to them, understand diagnoses, treatment options, and risks associated with treatment options, construct and structure their preferences, and make important health decisions; and (2) assess the impact of the new CDSS by making it available to women newly diagnosed with breast cancer and comparing it with two other existing technologies and a control group in a carefully designed experiment. The assessment of the impact will be made in terms of understanding of diagnoses, treatment options, and risks associated with treatment options, satisfaction with decisions made, amount of involvement in decision, compliance with decision, change in health status and change in quality of life. This report details the progress made in the development of the CDSS as well as overall enhancements to the CHESS system. The study design and protocol are described as well as the survey instruments developed for this study. Recruitment is just beginning for this study, therefore no results will be reported at this time.				
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Introduction:

The objectives of the research are to (1) develop an innovative computer-based decision support CDSS that will enable women with breast cancer to integrate the information available to them, understand diagnoses, treatment options, and risks associated with treatment options, construct and structure their preferences, and make important health decisions; and (2) assess the impact of the new CDSS by making it available to women newly diagnosed with breast cancer and comparing it with two other existing technologies and a control group in a carefully designed experiment. The assessment of the impact will be made in terms of understanding of diagnoses, treatment options, and risks associated with treatment options, satisfaction with decisions made, amount of involvement in decision, compliance with decision, change in health status and change in quality of life.

Specifically, we will compare three types of decision support technologies to a control group:

1. CHES: a new CDSS designed specifically to meet breast cancer patients' needs;
2. Internet: the rapidly proliferating Internet technology;
3. Audio Tapes: an audio-tape series produced by National Coalition for Cancer Survivorship called Cancer Survivor Toolbox. This self-learning audio program is designed to assist patients diagnosed with breast cancer from the time of diagnosis through the rest of life.
4. Control: standard patient education and any of the following books: Dr. Susan Love's Breast Book, Celebrate Life (a book on breast cancer aimed specifically at an African American population), and Breast Cancer? Let Me Check My Schedule.

Body:

- **Statement of Work Task 1:**

Develop and test of CHES enhancements (Months 1-15)

Develop and test new decision aid.

Accomplishments:

CHES is a system that can help people make important decision about their breast cancer treatment. While there are two tools in our service called "Decisions, Decisions" that are aimed specifically at helping women make decisions about surgery and other treatment options, CHES as a whole can be viewed as a Decision Tool. For instance some women learn best by talking to others. Hence the Discussion Group service within CHES becomes a crucial part of their decision support system. Others learn best by reading and thus Instant Library becomes an important part for them. Thus, since all aspects of CHES can be important pieces in a woman's decision support system we

have listed the enhancements that have been made to a number of the services within CHESS as well as overall design of the specific decision support programs.

1. Decision Notebook Service: This completely new service was developed for the grant and has been applied to three breast cancer decisions that women with breast cancer are faced with; Breast Surgery, Chemotherapy and Joining Clinical Trials.

The Decision Notebook:

- describes the options (e.g. standard chemotherapy, chemotherapy clinical trial, no chemotherapy),
- describes the Pros, Cons and Fine Print (or controversies) about the options
- describes what criteria other women used while making their decision
- allows women to rate the criteria against the options
- links to detailed information specific to an option.
- presents summary charts of the patient's rating of the concerns and options
- provides easy access to bookmarked items through out CHESS that the patient has marked and put into folders related to a specific decision (such as chemotherapy).

Numerous interviews were conducted with women with breast cancer as well as focus groups to determine concerns women faced and what sorts of information they needed and wanted in the process of making their decision. The decision notebook was been reviewed for accuracy of information and tested for usability. Ongoing testing and modifications will occur over the next month two months.

2. A second decision aid called "Learning from Others" was developed for those who prefer to learn in a more narrative style. Learning from Others covers the same material that is in Decision Notebook (such as concerns and options) but is presented in a narrative fashion where a user can read the information in a more linear fashion. Learning from Others includes streaming video clips from women who have already made that decision. Currently there is a decision about surgery in Learning from Others. A decision narrative about chemotherapy will be completed by the middle of August and will be immediately followed by one on clinical trials. Learning from Others also has a direct link to go to the Decision Notebook. Our intent is for women to use both Decision Aids – the Decision Notebook and Learning from Others.
3. Bookmarks was developed to allow the user to easily return to material in CHESS. The bookmarking function allows the user to tag a specific content in CHESS such as a Question and Answer, an Instant Library article, etc. The user can write notes about the information they tagged, and then can store that information in a number of folders (some of which are directly linked to the Decision Notebook). For instance if a woman was reading an Instant Library article about the survival rates between lumpectomy and mastectomy, she could bookmark that specific article. She would then be given the opportunity to write a note about that article. In this case she may write that the 5-year survival rate is the same for lumpectomy followed by radiation as with mastectomy. The women would then be able to put this into a folder called

Surgery. When she goes to the Surgery Decision Notebook her bookmarked items and her notes will appear, as well as a direct link to that article.

4. A new service called Breast Cancer Overviews was developed. This specifically for newly diagnosed patients who may wanted a limited amount of information to begin with. Currently there are three overviews on the following topics: Breast Cancer Basics, Surgery Overview and Chemotherapy Overview.
5. A Journaling service has been designed and will be ready for use by the end of August. This service allows women to write their thoughts about their breast cancer experience. There are guided exercises specifically designed to help women with breast cancer use the Journaling service the first time but there is also as an unguided journal.
6. Discussion Group Archives: Some past discussions about breast cancer decisions are very valuable to new CHESS users. As a result we have created Discussion Group Archives. Users can review past discussions on several decision-related issues such as surgery, chemotherapy, etc.
7. Discussion Group Introductions was added to allow users to easily identify users and know a little more about the history of other Discussion Group members. Users fill out a form that includes items such as their breast cancer diagnosis and treatment history, other interests, etc. Whenever they send a message to the discussion group, an introduction button appears so that other readers can review their introduction
8. Improvements to the Open Expert Messages in the Ask an Expert Service of CHESS. Over the years that CHESS has been available hundreds of questions have been asked of the experts. Many of the answers (and questions themselves) would be of interest to other women facing breast cancer decisions as a result. Open Experts messages was designed so that the experts can easily keyword an answer and transfer them to Open Messages which are accessible to all users. The Open Messages are now categorized by keywords to make them more accessible. Users are directly linked to the relevant Open Expert answers.
9. News Items was moved to have a more prominent place in the menu. Originally this service (designed to give users access to the latest news about breast cancer) was hidden in the Discussion Group section of CHESS. We moved it to the Services menu and have made it a direct link to the Breast Cancer Net newsroom.
10. Basic Web Skills was added as a CHESS service. This section of CHESS reviews the basics of searching the World Wide Web. The information and tips provided in this service are designed for people who are new to the Internet and perhaps even new to personal computers. In this service they learn the basic skills and information they need to move around the WEB.

11. Evaluating Web Info was developed and added as one of the Services within CHESS. This service is designed to help people understand how to be an informed WEB consumer. Users will learn the differences between .com, .edu, and .gov. They will also learn what questions to ask as they look at various sites, such as who funded the site, what are the credentials of the authors of the site, etc.
12. About CHESS is a new service that was developed to help users to understand more about CHESS. There are four basic areas that are covered in this service. They are; what is CHESS, why was CHESS developed, how is CHESS used, and who develops and funds CHESS.
13. A direct link to the Medline Plus Breast Cancer site is now available through CHESS. The National Library of Medicine's MEDLINE^{plus} information pages are designed to direct users to resources containing information about breast cancer. Users can search medical articles as well as connect to other government sites and resources.
14. A new browser was developed to be used specifically in this research for Use Data Collection. This browser is critical to understanding the use patterns of those involved in CHESS research. The Browser allows us to capture where a person goes within CHESS, how they navigate, how long they stay at each page, the amount of time it takes to download information once it is requested.
15. Update of all information in CHESS. A thorough review of all the information in CHESS was completed. New materials were added and outdated material was replaced. The following services within CHESS were reviewed and updated: Questions and Answers, Instant Library, Consumer Guide, Resources Directory, and Personal Stories.
16. A new design and look for CHESS was completed. This included a new way to navigate CHESS, categorizing services by areas, making templates for each CHESS service, and developing a CHESS logo. These graphic design changes were also incorporated in the support materials used in the study, such as the User Guide to CHESS. The main goal of the design changes were to make CHESS easier to use, particularly for those who have never used the Internet before, make the site more welcoming at first glance, and to add new capabilities to CHESS such as streaming video. (Appendix #1 – CHESS Services Menu)

- **Statement of Work Task 2.**

- Acquire and Prepare Equipment (Months 9-12)*

Accomplishments:

The 30 computers required for this study were purchased in May of 99. In the grant we had said that we would be using Web TV's. Unfortunately Web TV's have not

developed as quickly as was originally anticipated and it proved problematic to use them. For instance a big disadvantage to WEB TV's is that they are unable to support frames, thus making it difficult to navigate through a program such as CHESS. Moreover it too severely limited the graphics that could be used on CHESS. Since many WEB sites including CHESS use frames in the layout of the information, using WEB TV's at this time seemed unacceptable. After pursuing a variety of options we decided to purchase laptops for this study. Gateway computers gave us an equipment donation that allowed us to stay within budget while moving to this otherwise more expensive equipment. It should be noted that cost was a primary reason to move to WEB TV in the first place. But recently costs of computers have dropped to the point where they are virtually free with Internet access. Hence the cost advantage of WEB TV has become moot.

- **Statement of Work Task 3**

Refine research materials (Months 8-10)

Modify CHESS user manual to reflect the CHESS enhancements.

Develop user manuals for the Internet technology.

Develop and pilot test data collection forms.

Accomplishments:

Refine research materials: We have carefully refined our outcome measures and instruments to assess issues particularly critical to this research such as how well people can accurately assess the quality of information from a Web Site. Initially we did numerous telephone interviews with women who had formerly used the breast cancer module of CHESS to determine the set of outcome measures to be used. We also set up focus groups to further test these outcome measures.

Modify CHESS user manual: The user manual has been rewritten to reflect the enhancements and design changes to CHESS. The User manual is in the Appendix (Appendix # 2)

Develop user manual for the Internet technology: A user manual for those who get Internet access only (no access to CHESS) has been developed and is included in the Appendix (Appendix # 3)

Develop and pilot test data collection forms: As a result of the focus groups we developed and pilot tested a set of surveys for this study. These are included in the Appendix. (Appendix # 4 – 8).

- **Statement of Work Task 4**

Train staff from sites (Months 13-15)

Train site coordinators in study goals and rationale, subject identification and accrual, data collection, Internet installation and operation, and support for the video. Sites are previously trained in CHESS installation and operation but will be updated for CHESS enhancements.

Deliver materials to sites describing the project and conduct field tests of recruitment and study operation

Accomplishments:

(At the writing of this report we are at the end of month 13 of this project. As a result several of the following activities are still in process. We will summarize progress thus far).

It should be noted that there were site changes from the original proposal. Initially the three sites were University of Wisconsin Comprehensive Cancer Center (UWCCC), Harvard Pilgrim Health System, and the Little Red Door in Indianapolis. Due to changes in key personnel at the Little Red Door we replaced this site with the University of Wisconsin – Milwaukee School of Nursing, under the direction of Dr. Sandra Underwood. Dr. Underwood was recommended to us by Funmi Apantaku, the Midwest Director of the National Black Leadership Initiative on Cancer. Dr. Underwood has been working with African American women in Wisconsin who are diagnosed with breast cancer for a number of years and is an American Cancer Society Professor. She has been instrumental in recruiting African American women for video interviews for the CHESS decision programs and has a solid track record of outreach women with breast cancer in the African American community.

Mayo Cancer Clinic in Rochester, Minnesota is our third site. The Mayo Clinic replaced our original site, Harvard Pilgrim Health Care. Mayo Clinic is a member of the CHESS Health Education Consortium. Their strong reputation as a world-renowned health care provider, their commitment to research, and outreach in the area of patient education made them an excellent candidate for the third site for this study.

A concern that arose at all three sites was the arm of the study that proposed to use of the video Treatment Choices for Breast Cancer distributed by Health Dialog, Inc. Mayo Clinic had reviewed this material in the past and it was not approved for the Mayo Clinic Patient Education Center. After review of the newest edition of the video Mayo still refused to use this material because it did not match their clinical practice and they also felt that it was biased toward lumpectomy. The UWCCC reviewed it and were also unwilling to use it because some of the material was outdated. We had several conversations with the developers of this Shared Decision-Making video about the refusal of the clinics to use this program. We stated the concerns that the sites had about the program and our inability to get approval at these sites. After much discussion it was decided that using the Shared Decision-Making video Treatment Choices for Breast Cancer was not going to be possible in this study.

After reviewing many other alternatives we decided to replace the Treatment Choices for Breast Cancer video with a set of 6 audio tapes called the Cancer Survivor Toolbox: Building Skills That Work for You. These audio-tapes were produced by the National Coalition for Cancer Survivorship, the Oncology Nursing Society, the Association of Oncology Social Work and Genetch BioOncology. The goal of the audio-tapes is to help cancer patients develop practical tools in their daily life to deal with their cancer diagnosis and treatment. The tapes cover communication, finding information, making decisions, solving problems, negotiating, and standing up for your rights. Each tape provides information, interviews from cancer patients, and exercises to reinforce the skills discussed in the tape. All three sites have reviewed and approved the use of these audio-tapes.

Train staff from sites: The sites for training include Mayo Cancer Center in Rochester, Minnesota, University of Wisconsin Comprehensive Cancer Center (UWCCC) and University of Wisconsin - Milwaukee School of Nursing. Initial site visits to all three locations have taken place to make sure that each site understands the purpose and goals of the study and to build enthusiasm for the project. Dr. Gustafson or Dr. Sainfort went to the sites along with Ms. McTavish, the project director. A secondary site visit each clinic has been scheduled and will be completed by the end of July. The purpose of this visit is to deliver all the necessary equipment to the sites and go step by step through the protocol (Appendix #9) and obtaining informed consent (Appendix # 10). At this visit an in-home installation of the computer system (CHESS and Internet) is conducted to allow sites to walk through the actual process.

Note: Task 5 – 12 take place after the first progress report and therefore are not applicable at this time.

Task 5 . Recruit subjects, pre-test, assign and install (Months 16-30)
15 months after funding we will begin recruiting subjects, pre-testing, randomizing for the 4 groups, and installing software and Web TVs.

Task 6. Operate CHESS (Months 16-34)

Task 7. Collect Post-test data (Months 16-39)
Short form (1 page) decision surveys will be sent at weeks 2,4,6,8,and 10.
Longer form surveys will be sent to study participants at months 3 and 9. All surveys will be returned to the Madison Project Office.
Returns will be closely monitored to be sure the surveys are promptly returned and complete.
Follow-up contacts (including interviews, if needed) will collect surveys not returned and fill in incomplete or illegible data.

Task 8. Remove computers (Months 20-34)

Computers will be collected from users after four months in the home.

Task 9. Prepare the data for analysis (Months 17-40)

Task 10. Conduct Secondary Analyses (Months 20-36)

Begin baseline and secondary analyses.

Describe the study population and examine similarities and differences of the 4 groups.

Exploratory analyses will begin with this initial data set.

Task 11. Conduct Primary Analyses (Months 40-45)

Task 12. Prepare Final Report and Other Publications (Months 22-45)

Key Research Accomplishments:

Not Applicable at this time

Reportable Outcomes:

Not Applicable at this time

Conclusions:

Not Applicable at this time

References:

Not Applicable at this time

Appendix #1
CHESS Services Menu



CHESS
Comprehensive Health
Enhancement Support System

**Living with
Breast Cancer**

Topics | Dictionary | Bookmarks | Keywords | Help | Exit

Overview of Breast Cancer

Decision & Planning Guides

- Decisions, Decisions
- Action Plan
- Consumer Guide
- Resource Directory

Personal Space

- Health Tracking
- Assessments
- Journaling

A Network of Support



What's New

- CHESS News
- News Items

Reading Room

- Questions & Answers
- Instant Library

Beginner's Guide

- Basic Web Skills
- Getting Started
- About CHESS

Connecting with Others

- Personal Stories
- Discussion Group
- Ask an Expert

Other Sites

- Web Links
- Medline
- Evaluating Web Info.

Appendix #2
CHESS User Manual



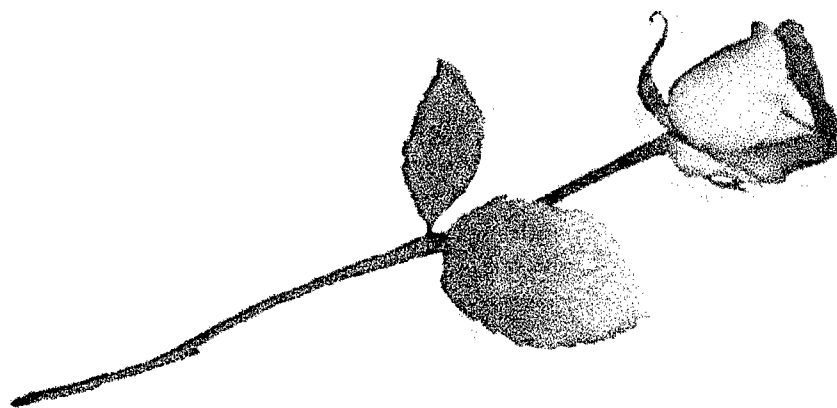
CHESS

Comprehensive Health
Enhancement Support System

User Support Manual

Living with Breast Cancer

<http://chess.chsra.wisc.edu/bc>



For technical support: 1-800-480-9223

For general help: 1-800-361-5481

How Do I Use a Mouse?

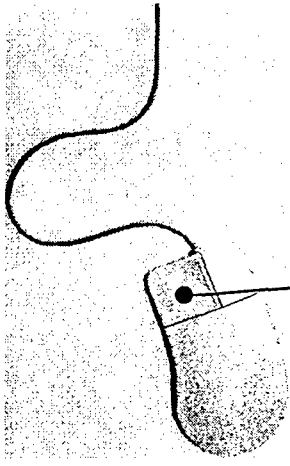


Figure 1

A mouse (Figure 1) is used to point to and click on items like buttons, hyperlinks or scroll bars on your computer screen. (To find out more about hyperlinks and scroll bars, see "What Do I Need to Know About the Screen?") Clicking on these items allows you to move from one place to another through the CHESS system.

To hold a mouse, place your hand lightly on top of it. If you are right-handed, position your index (pointer) finger on the left button and your middle finger on the right button. (The reverse if you are left-handed).

The **left button** will be the one you click on. *You will never have to click the right button when using CHESS.*

Move the mouse across a flat surface. As you move it, notice the cursor (either a small arrow or a "I" on the computer screen moves the same direction.

Clicking on a Hyperlink or Button

To click on a hyperlink or button, move the mouse till the cursor on your screen touches the hyperlink or button you want. Depending on what you are pointing at, the cursor may change to a small arrow or hand. Click once with your left mouse button. This will take you to the related pages.

Clicking on the Scroll Bar

To scroll (move) the page up or down on the screen, move the mouse till the cursor touches the scrollbar. (Figure 2) There are two ways to scroll.

1. Using the up or down arrows

- Position the cursor on the arrow above or below the grey bar.
- Click the left mouse button. This will make the move the page up or down, depending on which arrow you click on. For example, to see the top of the page, click on the up arrow.

2. Using the sliding bar

- Position the cursor on the darker grey bar.
- Press and hold the mouse button, and drag the bar in the direction you want the page to scroll (e.g. to see the bottom of the page, pull the bar downwards).

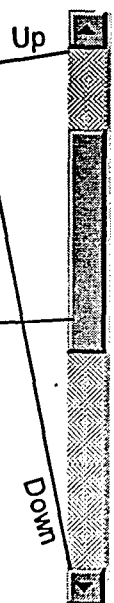
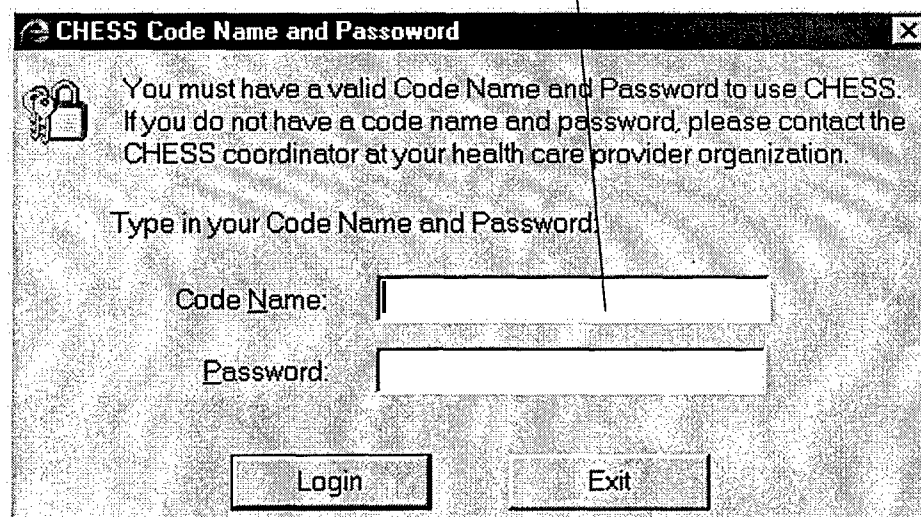


Figure 2

How Do I Start?

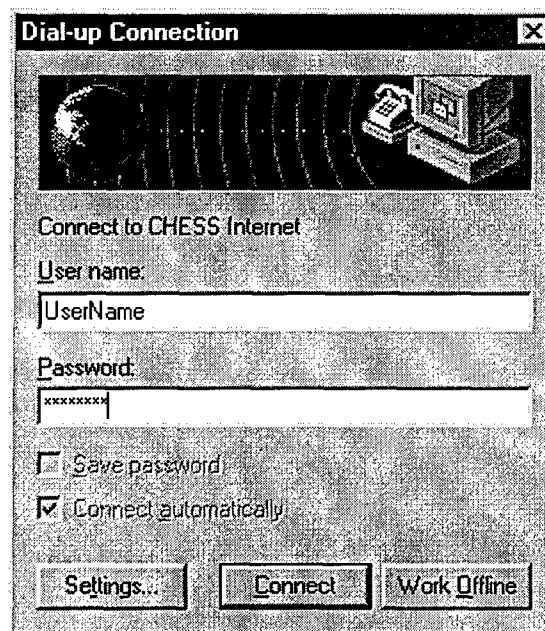
When you first turn your computer on, you will be asked for your CHESS code name and password (Figure 1). Type those in the spaces provided.



The screenshot shows a Windows-style dialog box titled "CHESS Code Name and Password". It contains a small icon of a padlock and a key. The text inside reads: "You must have a valid Code Name and Password to use CHESS. If you do not have a code name and password, please contact the CHESS coordinator at your health care provider organization." Below this, it says "Type in your Code Name and Password:". There are two input fields: "Code Name:" and "Password:". At the bottom, there are two buttons: "Login" and "Exit".

Figure 1

Once you click the "Login" button, the computer will dial your phone to connect to the Internet. While it is connecting, you will see this message (Figure 2). The computer should connect automatically, so you should not have to click on any buttons just yet.



The screenshot shows a Windows-style dialog box titled "Dial-up Connection". It features a graphic of a globe and a computer. The text inside reads: "Connect to CHESS Internet". Below this, there are two input fields: "User name:" and "Password:". The "User name:" field contains the text "UserName". The "Password:" field contains the text "xxxxxxx". Below these fields, there are two checkboxes: "Save password" (unchecked) and "Connect automatically" (checked). At the bottom, there are three buttons: "Settings...", "Connect", and "Work Offline".

Figure 2

Once your computer is finished dialing, CHESS will start automatically and you will finally see the CHESS introduction screen with a "Start" button. You can click on the "Start" button to begin CHESS.

START

On rare occasions the computer might forget your Dial-up User Name and Password. If this happens, you will see a screen that indicates you entered an "invalid user name or password" (Figure 3.) Just type them in again and the computer should remember them. If you experience any problems with this, call the CHESS help line at 1-800-480-9223

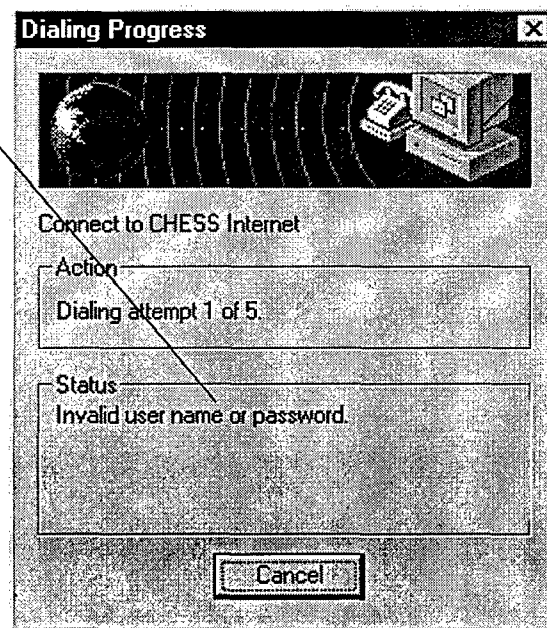


Figure 3

----- Cut Here -----

Keep these in a safe place: Your Username is _____

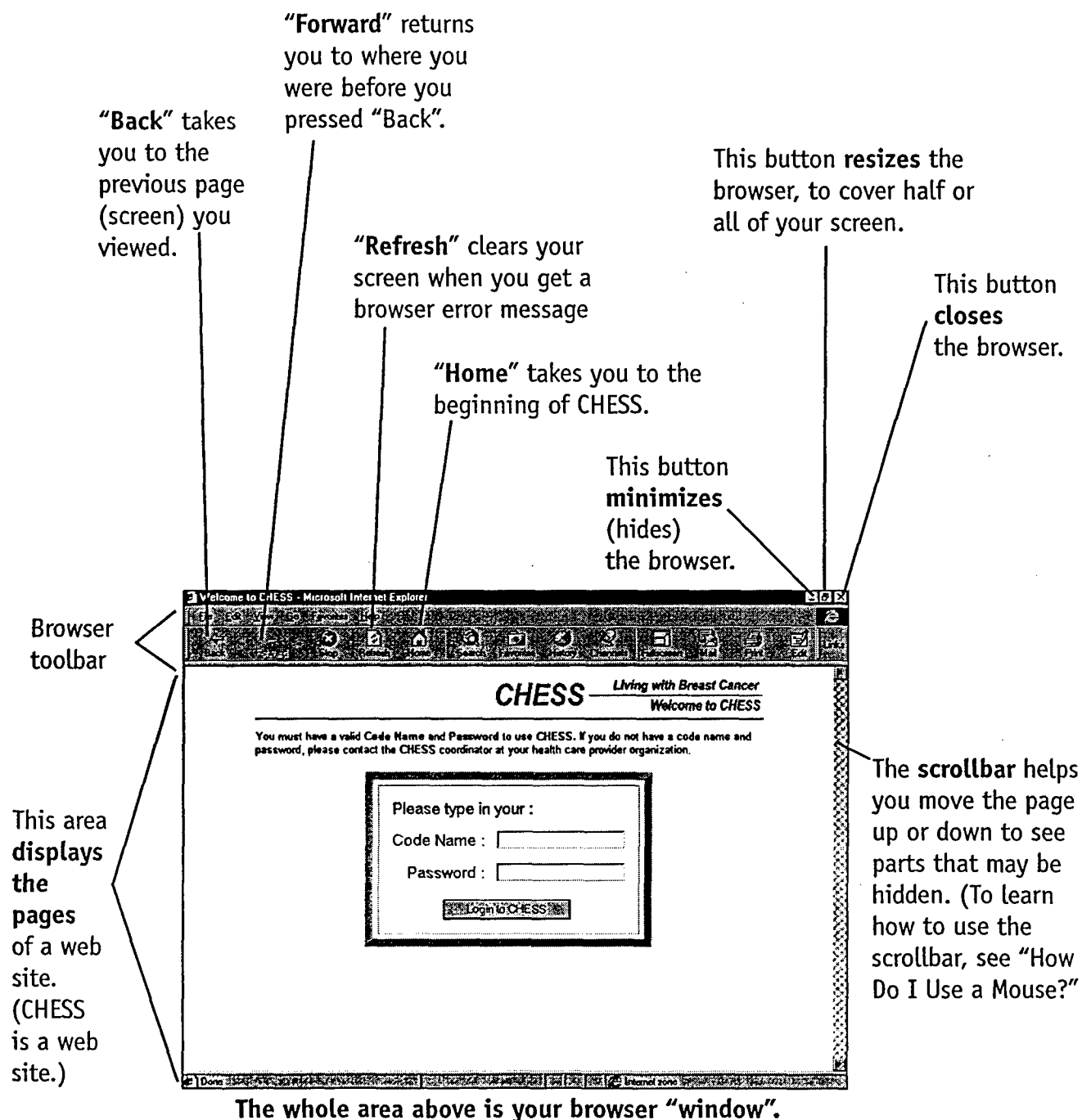
Your Password is _____

What Do I Need to Know About the Screen?



To view anything on the Internet (also known as "the Web"), your computer needs a browser. Think of a browser as a window through which you look, to view what's "out there" on the Internet. The browser connects to the Internet through your phone line. Microsoft's Explorer 4.0 (or newer) is the browser you will use to view CHESS. (See *How Do I Start?* for more information on starting CHESS.)

Handy things to know about the browser screen



Handy things to know about hyperlinks

Hyperlinks are words on a web page that are underlined and appear in a different color from other text on screen (usually dark blue). On a CHESS web page, hyperlinks appear in dark blue, purple or bolded black. They are always underlined.

For example, the following underlined words are hyperlinks you would find in a CHESS Topics Menu:

Overview - Detection and Prevention of Breast Cancer

Treatments

Emotional and Social Concerns

Menopause

Diet and Nutrition

Recurrence

Pain

Legal and Financial Issues

To find out more about a particular topic, place your cursor over the hyperlink and click the left mouse button once. This will take you to the next screen of related information.

To return to the previous screen, click the "Back" button on the browser toolbar.

If you have already clicked once on a hyperlink, in most cases the hyperlink color will change from dark blue to purple to indicate you have already viewed that page.

Some hyperlinks have a "roll-over" feature. For example, in CHESS Topics, the hyperlinks are bolded black underlined text (for easier reading). If you place (or "roll") the mouse cursor over a hyperlink, it will change color from black underlined text to blue. When the hyperlink changes to blue, you can click on it to go to a different page with more information.

Guide to Using CHESS

Getting Around CHESS

There are three ways to move around CHESS: the Services Page, the Web Browser and the Tool Bar.

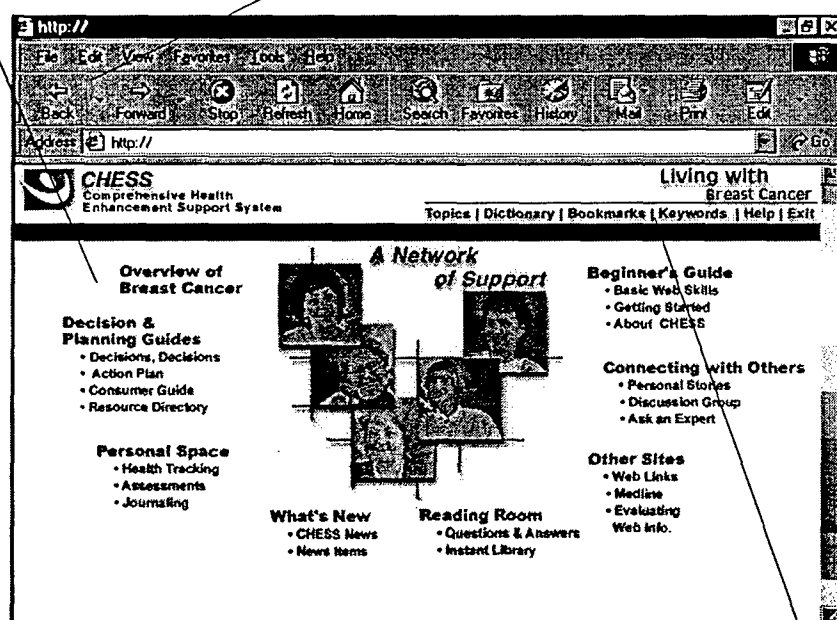
Services

The Services Page (Figure 1) contains links to all parts of the CHESS website. The information in CHESS is divided into eight sections, with additional categories in most sections.

Web Browser

There are some simple tools provided on the Web Browser to help you move around CHESS.

The **BACK** and **FORWARD** buttons are located on the browser toolbar at the left hand side of the screen. The **BACK** button allows you to go back to the previous screen you were viewing. When you go to another website from CHESS, you can use your **BACK** button to get back to CHESS. The **FORWARD** button allows you to move forward.



Scroll Bar:

You can move the screen up or down by either clicking on the scroll bar with the left hand mouse button and dragging the mouse up or down or by clicking on the arrows at the top or bottom of the screen.

Figure 1

CHESS Tool Bar

The list of words on the top right-hand side of the Services Page is called the Tool Bar. The Tool Bar will be in the same place on every page in CHESS. The Tool Bar includes:

Topics:

lets you search CHESS using different topics such as treatments or menopause.

Dictionary:

takes you to definitions of terms used in CHESS.

Keywords:

allows you to get all information in CHESS about a specific word or phrase.

Bookmarks:

electronically "bookmark" the screen you're reading in order to go back to it easily.

Help:

click on Help anywhere in CHESS and specific information about that section will appear.

Exit:

takes you out of CHESS.

What you need to know about CHESS

Getting Started: The web address for CHESS is <http://chess.chsra.wisc.edu/bc>. This will take you to the title screen (Figure 2). (If you need help getting to the title screen, see *How Do I Start CHESS?*) Using the mouse, click on the Start button to enter the website.

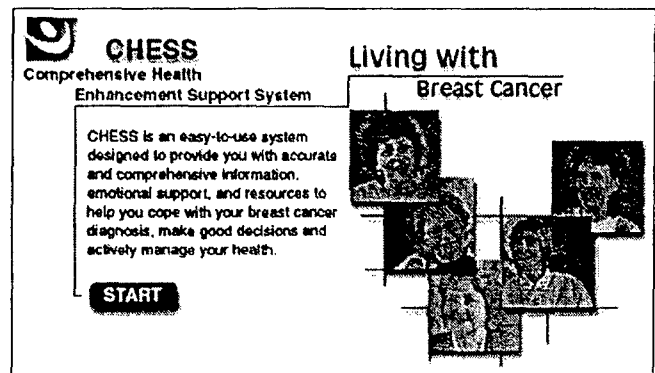


Figure 2

Code Name and Password: Each time you enter CHESS you will be asked to enter your code name and password (Figure 3). It is important to remember your code name and password. Anyone else

You must have a valid Code Name and Password to use CHESS. If you do not have a code name and password, please contact the CHESS coordinator at your health care provider organization.

Please type in your :

Code Name :

Password :

using CHESS in your home should have their own code name and password. This provides both system security and protects your confidentiality. If you forget your codename and password, or if someone in your household needs a codename and password, please request them from your CHESS coordinator.

Figure 3

Services:

This is the first page you come to after logging into CHESS (Figure 4). (It was also mentioned previously in "Getting Around CHESS")

From this page you can go to any service and all the content in CHESS, including:

Questions and Answers,

Instant Library, Decisions & Planning Guides, Personal Stories, Ask an Expert, Discussion Groups, Assessment, News Items, Web Links, Medline and others. You can see a description of each service by clicking on a main heading, such as Decision & Planning Guides, and rolling your mouse cursor over the choices on the menu. The description will appear on the right.

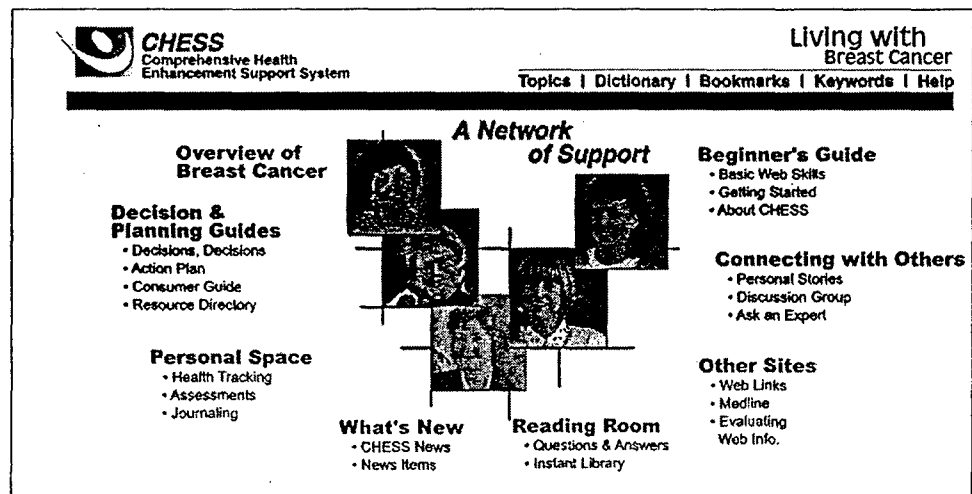


Figure 4

Keywords: To search **Keywords** for specific information within CHESS, click on the keywords button on the CHESS toolbar at the top right of the screen. You can either select a letter and see all the keywords beginning with that letter, or you can type in the word you want and CHESS will lead you to the services that have information about that keyword. When you select a service, you will get a list of items that have information about that keyword.

In addition, CHESS will automatically display  **Keywords** at the end of many documents that lead you to more related information.

Audio & Video: The CHESS website contains video clips of women sharing about their personal experience with breast cancer. To watch one of the videos, simply click on a photo of one of the women. **Your computer may or may not be able to play video or broadcast audio.** You will still see the video player on your screen (Figure 5), but it will not be activated. However, you will be able to read the text of what the woman says in the video and see her photo.

If your computer IS able to play audio and video, simply use the buttons provided on the video player (Figure 5). Click on the Play button to start the video; Click the Pause button to stop it at any point along the way; or Click the Stop button to stop the video. The video will start from the beginning after you click Stop, but will continue on from the point where you press Pause.

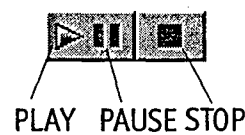



Figure 5

Exit: When you click on the **Exit** button, you will go to the Start page. From here you can close your web browser by clicking on the  button at the top far right of the screen and then clicking YES to disconnect in the box that pops up.

CHES: Breast Cancer Services

What You'll Find in CHES



Overview of Breast Cancer

The **Overview** contains some basic information about breast cancer and the treatment options available to you.



Decision & Planning Guides

Decisions, Decisions helps you think through difficult decisions you may be facing, specifically surgery, chemotherapy and clinical trials.

Resource Directory is a list of national health and social service resources for dealing with breast cancer. Descriptions of each resource with contact information, including direct links to available web sites are provided.

Consumer Guide can help you understand what health and social services are available, how they work, and how to find a good provider.

Action Plan is a step-by-step guide to help you carry out a change in your diet and identify and overcome barriers to your success.



Personal Space

Health Tracking helps you track your health status over time, and provides graphs of your progress as well as links to related CHES information.

Journaling is a place for you to record your thoughts, feelings and experiences. Helpful tips are provided to get you started on journaling.

Assessments helps you assess your health risks and behavior and provides feedback on how to improve your situation.



What's New

News Items is a link to a website where you can find up to date news articles on issues related to breast cancer.

CHES News provides you with updates on the newest information and features available in CHES.



Reading Room

Questions and Answers addresses many commonly asked questions related to breast cancer. The answers are simple and specific, with keyword links to more detailed information in other CHES services.

Instant Library is a database of articles, brochures and pamphlets related to breast cancer. It directly links to relevant articles at other Web sites.



Other Sites

Web Links describes and provides a direct link to selected Web sites that have high-quality and relevant information about managing your health condition.

Evaluating Web Info is a website where you will find guidance to help you become a critical user of the information available on the Web.

Medline is a website maintained by the National Library of Medicine. The site provides a carefully selected list of links to breast cancer resources on the Web to help you research your health questions.



Connecting with Others

Personal Stories are real-life accounts of people living and coping with breast cancer. Many of the stories contain information that can help you deal with your own situation.

Ask an Expert allows you to anonymously ask experts questions about medical, social, financial, spiritual, or emotional topics. You will receive a confidential response within two business days.

Discussion Group is an on-line support group which allows anonymous, non-threatening communication among people facing breast cancer. You can share information, experiences, hopes and fears, and offer different perspectives.



Beginner's Guide

Basic Web Skills is a resource to help you learn how the Web works, what it offers, and how to find the information you want.

About CHES contains some of the history behind CHES and how it has evolved into what it is today.

Getting Started can show you how to get the most out of the information in CHES, understand better how to move around CHES or where to call for HELP!

How Do I Exit CHESS?

1. **DO NOT** just shut the computer off. Modern computers must be shut down properly, otherwise they can be damaged.
2. When you are done, click the "x" in the upper right hand corner of any CHESS screen. (Figure 1)

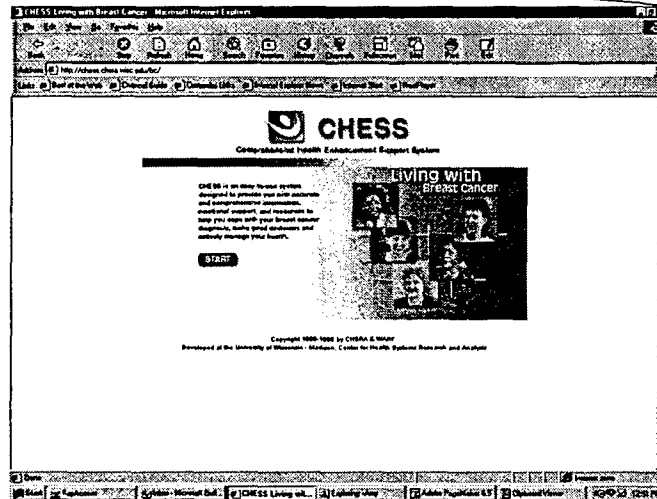


Figure 1

3. To disconnect your computer from the Internet, double-click on the two attached computers down in the bottom right-hand side of your screen (Figure 2).



Figure 2

4. A box will appear in the middle of your screen that looks like this (Figure 3). Click the Disconnect button to disconnect your computer from the Internet.

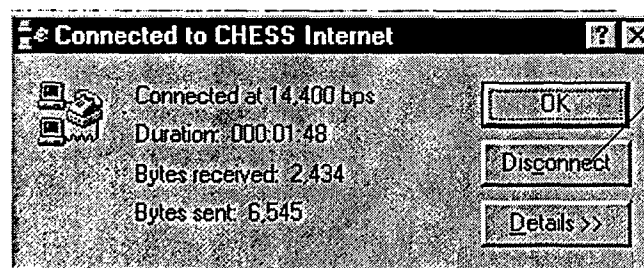


Figure 3

4. To turn off your computer, click on the "Start" button on the lower left hand corner of your screen. (Figure 4)
5. Then click once on "Shut Down..."

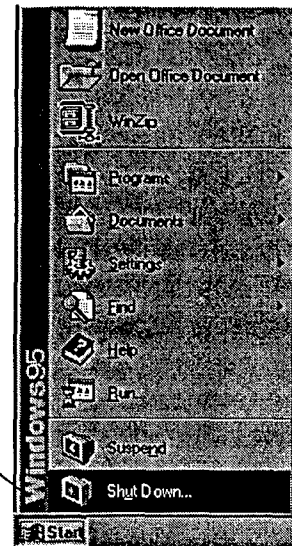


Figure 4

6. Another message will then pop up. (Figure 5)
7. Choose "Yes".

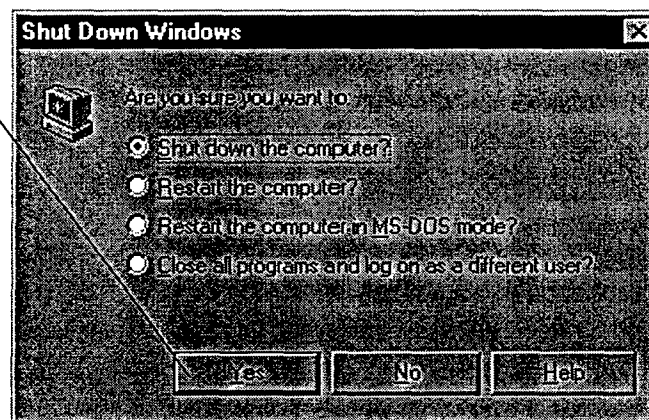


Figure 5

8. When your computer says "It's now safe to turn off your computer", press the power switch to shut off the computer.

CHESSTroubleshooting Guide for Internet Explorer

What Is The Internet Anyway?

The Internet is basically a large bunch of people using computers that are connected together with telephone lines, cable lines, or via satellite. Computers from other continents are connected to North America by large fiber optic communication lines that run along the ocean floor. Nobody knows how many computers make up the Internet. But, the best guess is that there are some thirty to thirty-eight million people that are on-line. New computers and people are constantly being added to the Internet.



No individual, no corporation and no government owns the Internet - it is owned, operated and maintained jointly by all of those who use it, (including *you!*). Because of this, there are a number of things that can happen as the Internet operates. People make mistakes, computers break down, and phone lines get overloaded or broken. When this happens, you may get an error message indicating that something is wrong. But, it is usually temporary and can be easily dealt with.

What If I Have Problems With Connecting To The Internet?

In order to connect to the Internet, your computer needs to use your phone. If, however, your computer refuses to dial your phone or it dials the phone, but says "Authentication" and asks you for a username and password. It is NOT asking for you CHESST codename and password. This message merely indicates that your computer has forgotten some information. If this happens to you, call the CHESST help line at 1-800-480-9223 to get instructions on how to enter that information back into your computer.

What Do I Do When I Get An Error Message?

These error messages are just the computer's way of telling you that there is something wrong with the Internet. Most of the time, you can just wait a few minutes for someone to fix the problem and try again. So, the first things you want to try when you get an error message are the following:

Wait a few seconds and then click on your "Refresh" button. (Located on the upper middle part of your screen)	
If the problem is not fixed within a few minutes, then click the "Back" button to go back to the previous page (You can always come back later and see if the problem has been fixed). (Located on the upper left part of your screen)	

What Do the Error Messages Mean?

The following chart contains some of the more common error messages and their causes. If you encounter one of these errors while using CHESS and cannot clear it by using the steps outlined in the chart, call the CHESS help line at 1-800-480-9223 for assistance.

Error Message	Cause	Solution
"Authentication" <i>Computer is asking for a user name and password.</i>	Your computer has lost some information that it needs to proceed.	Click the "Cancel" button. Then call the CHESS help line at 1-800-480-9223 for instructions on how to enter that information back into your computer.
404 Not Found	The browser could not find the specific document that you requested from the internet. The document may have been removed, had its name changed, or have been moved to a new location. This is a problem at the other end and has nothing to do with your computer.	To return to your previous page, click on the Back button.
403 Forbidden/Access Denied	The Web site you requested requires special permission in order to access it (maybe a password).	To return to your previous page, click on the Back button.
503 Service Unavailable	The host computer is too busy. Try viewing the page again after about 30 seconds.	You can try again by clicking on the Refresh button. To return to your previous page, click on the Back button.
Internet Explorer Script Error <i>Do you want to continue running scripts on this page?</i>	The document you are trying to view has an error in it or the document was garbled. This usually has nothing to do with your computer.	Click on the "Yes" button to continue. You may have to do this several times.
Bad File Request	The document you are trying view has an error in it. This is a problem at the other end and has nothing to do with your computer.	To return to your previous page, hit the Back button.
Cannot Add Form Submission Result to Bookmark List	The results of a form that requires you to enter information (such as a search) cannot be saved as a bookmark. A bookmark can only be a document or an address.	To return to your previous page, click the OK button.
Warning: Page has Expired	The page you requested was created using information you typed into your computer. As a privacy precaution, Internet Explorer does not automatically resend your information to the other computer.	You must explicitly tell Internet Explorer to resend your information and view this Web page. To resend the information, click the Refresh button
Connection Refused by Host	The Web site you requested requires special permission in order to access it. Unless you have this permission, you will not be able to view the site.	To return to your previous page, hit the Back button.
Failed DNS Lookup	This can be caused by a misspelling in the internet address. Or, it can also be caused by too many people trying to look at a web site at once. Perhaps you might try again in 30 seconds.	To return to your previous page, click the Back button.

Error Message	Cause	Solution
<i>Failed DNS Lookup</i>	This can be caused by a misspelling in the internet address. Or, it can also be caused by too many people trying to look at a web site at once. Perhaps you might try again in 30 seconds.	To return to your previous page, click the Back button.
<i>Connection with the server could not be established</i>	This usually means that the internet address is wrong in some way. Or, the address may not exist at all. This can also be caused by too many people trying to look at the web site at once. Perhaps you might try again in 30 seconds.	Click on the OK button to proceed. You may need to use the Back button to return to your previous page.
<i>File Contains no Data</i>	The browser found the site, but the file is blank. This is a problem at the other end and has nothing to do with your computer.	To return to your previous page, click the Back button.
<i>Helper Application not Found</i>	This error occurs when you try to download a file that needs to use a special program to run. If you don't have the special program on your computer, you will get this error. Examples of the type of files that need helper applications would be sound or video files.	Click on the OK button to proceed. You will not be able to run these files.
<i>Not Found</i>	The link no longer exists. This is a problem at the other end and has nothing to do with your computer.	Click on the OK button to proceed.
<i>Site Unavailable</i>	Too many users are trying to access the site, the site is down for maintenance, there is noise on the line, or the site no longer exists. This can also be caused by typing in the wrong internet address.	Click on the OK button to proceed. You may need to use the Back button to return to your previous page.
<i>TCP Error Encountered While Sending Request to Server</i>	This error is caused by erroneous data on the line between you and the requested site. This may be a problem with your computer or phone line.	Click the OK button to proceed. You may need to use the Back button to return to your previous page. If the problem persists, report the error to the CHESS help line at 1-800-480-9223.
<i>Too Many Users</i>	The site is busy. You may want to try again after about 30 seconds.	Click the OK button to proceed. You may need to use the Back button to return to your previous page.
<i>Unable to Locate Host</i>	Your request did not return anything, the site is unavailable, or the Internet connection was dropped. This is usually a problem at the other end and has nothing to do with your computer.	Click on the OK button to proceed. But, if you get this message all the time, you should call the CHESS help line at 1-800-423-9223.

Appendix #3
Internet User Manual

Internet User Manual

(Basic Web Skills)

**Information and Tips about the Internet
and How to Use It**

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BASIC WEB SKILLS INFORMATION

Welcome! This section reviews the basics of searching the World Wide Web. The information and tips provided here are designed for people who are new to the Internet and perhaps even new to personal computers. Here, you will learn the basic skills and information you need to get going on the Web and, with a little practice, you'll quickly pick up the rest.

As you begin to use the Internet, you may be confused or overwhelmed by the sheer volume of information, entertainment, and really bad design that's out there. Don't let it intimidate you; the Internet is really just another form of library, and like a library, there is a way to find the information it contains. Think of the Internet as a new information-seeking tool.

Remember to relax and have some fun with this technology. Before you know it, you'll be using it like a pro!

THE INTERNET DEFINED

What is the Internet?

The Internet (also known as cyberspace, the Information Superhighway, and the Net) is a global network of computers linked together to send and receive information. The computers are joined through high-speed connections using satellites, cables, and phone lines. All these computers are considered part of the Internet because they speak a common language -- or protocol (called the Transmission Control Protocol / Internet Protocol -- or TCP/IP). TCP/IP is what makes it possible for your personal computer to communicate with another computer on the other side of the world.

Where did the Internet come from?

The Internet evolved from a Defense Department project in the late 1960s to link military researchers at four universities. It was designed as a decentralized network so that it couldn't be knocked out by a single nuclear attack. During the 1980s, the Internet was adopted by the National Science Foundation that provided funding to make it available to a wider array of scientists and researchers. Later it was opened up for commercial use. The Internet is now an international network of at least 60,000 smaller, independent computer networks.

Who's in charge of the Internet?

The simple answer is that there is no one group that is in charge of the Internet, although a number of companies have played major roles in putting the framework together (CompuServe, America Online, Microsoft, MCI and Netscape, to name a few). There are also several international organizations that are concerned with creating technical standards and discussing the Web's programming languages. But in large part, the Internet is actually run by local computer administrators who are responsible for maintaining the individual computers that are part of the larger network of computers that forms the Internet. The person running an Internet site computer system is called a **Webmaster** or **Web Manager**. So, if you object to material located on a certain Internet site, the person you could contact would be that site's Webmaster. Or, say you are having connection problems; the person you should call would be the company supplying your connection.

GETTING ONLINE

How do I hook up to the Internet?

To hook up to the Internet, you simply connect your personal computer to one of the computers that is part of the Internet. To connect your computer to another computer, you use an Internet Service Provider or ISP. Once you are online (connected to another computer via your phone line), your computer can talk to any other computer on the Internet, whether its in your hometown or on the other side of the world.

Am I charged for a long distance phone call when I connect to a web site in another state or country?

No, you pay only for the local telephone call* that connects your computer to a computer that is hooked into the Internet. At this time, the Web transfers information using computer lines and other non-telephone connections, so long distance charges are not incurred. The only other charge that you may incur is the subscription fee for an Internet Service Provider (ISP) or an Online Service.

*** Exception:** Internet users in rural areas may have to pay a long distance fee if their ISP is not within their local telephone billing area.

What are Internet Service Providers (ISPs) and Online Services?

ISPs and online services are commercial services that provide a gateway between your computer and the Internet. The distinctions between the two are starting to blur, but generally, ISPs simply provide a connection to the Internet, and online services provide a connection to the Internet as well as special services available only to their subscribers. Some major online services include America Online, CompuServe, Microsoft Network, and Prodigy.

Generally, ISP and Online Service subscribers pay a monthly membership fee (about \$10-\$20) in addition to a per hour charge after the first few hours. This fee covers the costs of buying and maintaining the expensive computers and leased lines that are necessary to hook into the Internet. Check around to see what is the best deal for you. Not all ISPs are the same.

Note that some businesses and schools provide connections to the Internet for their employees and students. If your work or school provides Internet access, you won't need to pay for an ISP or Online Service.

What are web servers and clients?

Simply put, the Internet is a lot of computers that are linked together. When you go online, your computer is linking (via your phone line) to a computer. You can't link to any old computer though; you have to link to a computer that allows external access by other computers and has the right software to process requests for files or web pages. This kind of computer is called a **web server**. A web server is a computer that stores web pages and makes them available for outside access. A web server sends files across the network where your computer receives and interprets them.

When you're online, your computer is the **client**. When you tell your computer to bring you to your homepage, your client communicates with the web server where the files are located. It's important to understand that navigating the Internet involves nothing more than telling a computer where to find the file you'd like.

A web server is generally hooked up 24-hours a day, ready to serve your needs. When it receives a request, it responds by sending the requested file. A web server may get only a few requests in a day or it may get millions. Each request it gets is called a **hit**.

WEBSITE STUFF

What is a web page?

A **web page** is a single file that can be displayed on the Web. Some web pages are just a few lines of text and others have as much text as several book pages. Here's the key: if you can get to all the information by just scrolling (moving up and down in the page by clicking on the triangle arrows on the right side of your screen), it's all one web page. If you have to "click here" or use your mouse to select additional information, you've gone to a new web page -- which may or may not be at the same web site. Web pages can be made up of writing, pictures, sound, animation and video.

What is a web site?

A **web site** is a collection of one or more web pages linked for a common purpose with a common theme. A web site may have a single page -- or it may have thousands -- or anywhere in between. Web sites are often contained at a single physical location, reside on a single server computer, and may have a single author or multiple authors.

How are web pages and web sites created?

Web pages are created using a computer language called the Hyper Text Markup Language (HTML). This may sound complicated but it really isn't. HTML is basically instructions telling your computer how to display text and graphics and how to link to other sites.

MOVING AROUND THE INTERNET

What is a Web Browser and which one do I have?

A **browser** (also called a **client**) is a type of software that enables you to search the Web and display web pages. Browsers can also help you transfer files, and send and read electronic mail. Your browser starts once you connect to the Internet.

The two most widely used browser programs are **Netscape Navigator** and Microsoft's **Internet Explorer**. Every year these programs are improved and newer versions are released. To check to see which browser version you have, click on the Help Menu on the bar at the very top of your screen, and then select "About Netscape" or "About Internet Explorer." This will display a window showing which version you have.

What is a hyperlink and how can I spot one?

Hyperlinks (or **links**) are hidden instructions buried in a web page that make it possible for you to jump (or "navigate") from place to place on the Web. When you click on a link, the instructions tell your computer to display a connected web page. Clicking on a link can take you to another place on the same web page, to another page in the same site, or to another site altogether.

So what does a link look like? Links can be text, a picture, or an image. They can be anywhere on a page, and sometimes they are almost invisible. There is one sure way to check to see if something is linked: place your mouse pointer over the text or image. If your pointer turns into a little hand with one finger extended, you are on a link. To activate the link, just click, and you will be instantly transported to another web page that has been connected with the current page.

Every time you click on highlighted text to go to another page on the Web, you're following a link. **Text links** (also called **hypertext**) are usually underlined and of a different color (the standard color is blue). **Graphical links** (pictures or images) are often accompanied by instructions (for example, "click here to continue"), and sometimes have borders.

Links have good and bad points. Links can take you to interesting and relevant sites, and can make research fast and easy. Without links, you'd be stuck on the same web page forever! However, one drawback to links is that they can take you further and further from your original web site. Also, they

are not necessarily an efficient way to find specific information since you don't really know where you're going until you get there, and several clicks in you may not remember just how to get back to an earlier item.

Is there something wrong with my computer when I click on a link and nothing happens?

Probably not. Just like your local freeways at rush hour, the Internet gets traffic jams at times. The best way out is to click on the "Stop" button in your browser bar at the top of your screen, and then try clicking on the link again. If it is still taking a long time, try waiting a few minutes for things to settle down. This often clears things up. The problem is usually with the computer you are trying to connect to, not your computer.

How can I move from one web page to another web page?

At the top of your browser window, you'll see a bar with buttons. These buttons will help you get around the web. There are a four key ways to move around on the Web:

1. Type in the address of the web site you would like to visit.
2. Use your **Forward and Back buttons** on your browser's toolbar.
3. Use your **Go** function to select previously visited sites from your current browsing session.
4. Bookmark the web site for future access.

What is an URL?

URL (pronounced "earl" or spelled out as U.R.L.) stands for **Uniform Resource Locator**, but you certainly don't need to remember that! What you do need to know is that an URL is a web page's address on the Internet. Every document or resource on the Internet has a unique URL. The URL tells the software running the Internet where the page you want is located so it can be retrieved and sent to your computer.

Just like a postal address, which requires a street address, city, state and zip, a URL requires certain parts necessary to distinguish it from all other web pages.

What are the different parts of an URL (web address)?

Each web address (URL) can be broken into three parts. Reading an address from left to right they are the **protocol** (such as http://, ftp://, gopher://); the **server** or **domain name** (everything before the

first single forward slash); and the **file path** and **filename** (everything after and including the first single forward slash).

Let's take, for example, the address <http://www2.cancer.org/contact/> (the address for the American Cancer Society's Contact Page on their Website). It may look ridiculously complicated, but we'll make some sense of it. First of all, a period is always called a "dot". A "dot" separates major parts of the address, a "slash" separates subdivisions of the main parts. A "dash" is used to connect words, since spaces are not allowed in a URL. Let's break this URL down:

http://

This part tells the computer what type of protocol (or computer language) to use to read the web page. Http stands for "Hyper Text Transfer Protocol." It's the same for virtually every page so you really don't need to be concerned with it. You probably don't even need to include "http" in typing in an URL because your browser assumes that you're looking for an "http" page.

www2.cancer.

This is called the domain name - the registered name of the computer holding the web page and the directory. Note that the domain name is followed by another "dot".

org/

Next you'll see a code which identifies the type of domain site (who owns and operates the web site). There are seven basic types:

- com - commercial
- edu - educational institution
- gov - governmental body
- int - organizations established by international treaty
- org - nonprofit organization
- mil - military services
- net - Internet gateway or administrative host

Most sites outside the United States use a two-letter code which identifies the country rather than one of the three-letter codes above, such as "au" for Australia or "fr" for France.

Contact/

This is the final part of the URL. It tells your computer the name of the file that makes up the page.

How can I visit a web site whose address (URL) I already know?

If you know the web address of the site you want to visit, you can enter it one of two ways:

1. Type the URL directly into the **Address** or **Location** line (at the top of your browser window, below the Back button), then hit the **Enter key** on your keyboard.
2. From the browser bar at the top of your page, click on File. From the pull-down menu, select **Open** or **Open Page**, and type the URL into the box that appears.

How do I use the Back and Forward buttons?

At the top of your Browser, the very top left-hand button is marked **Back** and/or has a little arrow pointing to the left and the button next to it is marked **Forward** and/or has a little arrow pointing to the right. With these buttons, you can flip back and forward through web pages you have visited during your current search (in other words, these buttons will display only those web pages you have viewed during your current sitting, not web pages from yesterday or last week).

To use the Back button, simply click on it and you will be returned to the page you were viewing just before the current one. If you see another link that looks interesting on your way, you may choose to follow it. To use the Forward button, simply click on it and you will go to the page you were viewing just after the current one.

Notice that after you've followed a link and then returned to the original page, the color of the link has changed (usually from blue to purple unless the web page designer has chosen other colors for the page). A changed color means that you've already followed that link.

How do I use the Go function?

You can use your Go function to select previously visited sites from your current browsing session. Go is temporary, and will erase when you quit your search session.

To use the Go function in Internet Explorer (notice: there isn't a button labeled "Go"),

1. Next to the Forward and Back Arrow Buttons at the top of your Browser bar, you'll see little triangles that point down. If you put your cursor over the arrow, a list of all the sites you have visited during your current search session will appear. To select a site, simply click on the site of your choice from this list.

To use the Go function in Netscape Navigator,

1. Click on Go menu and look at the list. Go records the web sites you've visited during this Netscape session. Select a location from the Go menu by simply clicking on the web site of your choice.

MARKING YOUR PLACE

What is a browser bookmark (or favorite)?

Perhaps the best way to find sites that you visit regularly is to **bookmark** them. Just like the cardboard ones that you stick into a printed book, a browser bookmark is a placeholder to a particular URL (web address) that you set using your browser software for ready access later.

Netscape Navigator calls this feature **Bookmarks** while Internet Explorer calls it **Favorites**. In both cases, this browser feature allows you to store a list of web pages so you can go back anytime without having to remember and type in the actual URL (web address).

How do I make and revisit a bookmark/favorite?

If you find a web site you'd like to revisit, just click on the word Bookmarks or Favorites at the very top of your screen. A menu will appear with the option to add a Bookmark or Favorite; click on this option to add the current web page URL to your list of Bookmarks/Favorites.

The next time you want to visit that web page, simply click on the site name from same Bookmarks/Favorites menu. To organize or delete web sites from your Bookmarks/Favorites list, look under the Bookmarks/Favorites menu, and select Edit Bookmarks or Organize Favorites. This will open your Bookmarks/Favorites file and you can edit, delete and organize them from there.

USING THE WEB

What does "surfing the Web" mean?

One of the most enjoyable aspects of the Internet is browsing various web sites - or "surfing the Web." It's a phrase referring to the hopping from place to place on the World Wide Web using hyperlinks. It's rather like going down to a large bookstore and wandering around according to some strategy. For example, you might head straight for the sales clerk and ask for a specific book by title or author. Or you might head for the section of books of interest to you, e.g., sports, travel, cooking, history, fiction, etc. Perhaps you just start wandering up and down the aisles waiting for something to catch your attention. Regardless of the strategy you use, you will eventually come across a book that you will pick up and browse through, maybe reading a paragraph or two, glance at a few pictures, and maybe even check the table of contents. This brief encounter will enable you to decide whether you should put the book back, buy it, or carry it around as a possible purchase.

Well, the Internet can be viewed as the greatest bookstore in the world, with web sites much like books containing pages of text and pictures and even sound and video clips. Once you understand a few basics to finding and moving around web sites, browsing on the Web can lead to the discovery of other information. Perhaps you are intent on tracking down a specific piece of information or a person. Or you maybe you'd like to pick an area of interest and find a listing of web sites with information on that topic. Once you find a web site of interest and check out a few pages, you might decide to bookmark the web page so you can easily return later. You could spend a couple of hours reading, looking at pictures, browsing over the comments in an online forum, chatting live online with others with similar interests, or sending an e-mail inquiry about a topic, product, or person.

Surfing the Internet, like browsing a bookstore, can be a fun and productive experience. It can also be rather tiring, like the information overload you might experience after a few hours in a bookstore. Many people spend 1 to 3 hours surfing in the evening or on the weekend as a leisure activity. If you want to broaden your horizons and knowledge, surfing the net is a great way to do it.

SEARCHING FOR INFORMATION

How do I search for a particular topic on the Web?

The best way to find information on the Web is to use a **search engine** - a site that provides the ability to search for information on the Internet. Search engines are like giant card catalogs available to us (for free!) on the Web. There's been tremendous growth in the number of search engines, but no single source has been able to catalog every single Web page. The total number of web pages is just too big, growing too rapidly, and with very little organization or control. So a thorough search still may require using more than one search engine.

Another way to search the web is to find a site that has its own search function built into its web site, like the American Cancer Society.

What are some of the more popular search engines?

There are numerous search engines on the Web. Some of the most commonly used are listed below. Each engine works with keywords and phrases, and each engine has a little tutorial.

All in One Search	http://www.allonesearch.com/
AltaVista	http://www.altavista.com/
Ask Jeeves	http://www.aj.com/
Excite	http://www.excite.com/
HotBot	http://www.hotbot.com/Infoseek
Infoseek	http://www.infoseek.go.com/
Lycos	http://www.lycos.com/
Magellan	http://magellan.excite.com/
Webcrawler	http://www.webcrawler.com/
Yahoo	http://www.yahoo.com/

Whatever search engine you use be sure to check out its help system for rules, tips and syntax. Almost all search engines use "Boolean logic" which allows you to narrow or broaden your search with terms like AND, OR, NOT or NEAR.

TIP: Add any search engine sites above that you really like to your browser bookmarks/favorites for future use!

How do I perform a search using a search engine?

To perform a search, simply enter one or more keywords into the blank box provided and then click on the Search button. The search engine will look through its catalog of pages and return a list of links to pages that contain at least one of your keywords in either its name or in a special descriptive paragraph which has been submitted to the search engine by the site administrator. A few search engines now claim to search the entire text of each page. Remember computers are literal: they don't understand what they read; they just match on it. So you can get lists of sites that have next to nothing to do with what you're really searching for.

TIPS:

1. Be sure to try several different search engines when looking for information since each one can have different listings included in its database.
2. Experiment with putting the words that you are searching for in quotes.
3. Try narrowing your search down by using the search options menu. For example, at Yahoo, next to the search button, click options. Then try one of the search options such as "an exact phrase match." Also at Yahoo, after you receive your search results, you can then scroll down to the bottom of the page and just click on the other search engines that are listed. You will then get the search results from those search engines.

Are there different types of search engines?

There are basically two types of search engines on the Web: the index, and the directory or subject guide. One way to think of the differences between these two kinds of engines is to think of web sites as books. Indexes catalog every word in every book it looks at, and will list for you each page that contains word(s) you're looking for. Directories and Subject Guides take the overall subject matter of the books it looks at and lists the front covers of the books that match your word(s). The advantage of index search engines is also their disadvantage: they are incredibly inclusive, so if there is a site with the word you're looking for, there is a good chance that these search engines will find it. The bad news is that you may find far too many sites and you will likely have to sift through a lot to find what you are looking for. Directories and Subject Guides, on the other hand, are less thorough and will often result in a shorter list of search results.

Two popular Index search engines are Alta Vista and Hot Bot. Yahoo and Magellan are examples of Directory/Subject Guide driven search engines. Some search engines use both types of search functions, that is, they are both an index and a directory, like Infoseek and Excite.

Which search engine is the best?

Each search engine has its own way of compiling and collecting information, and therefore each produces different results. To illustrate this point, try using a variety of search engines to look for information on your favorite hobby. You'll see the radically different hits you'll get with each directory and index.

Remember that no one service is perfect, so use as many as you have time for. Using many search engines will also help you get a feel for how the different kinds of services work. You'll soon find yourself using a favorite engine to find all the information you need quickly and painlessly.

How can I perform a search within a single web site?

Really large web sites, like the American Cancer Society, can contain thousands of web pages. This makes even the most well conceived navigation system awkward. A common technique then is to add a search feature to the web site. This allows the reader to enter a few words and the server will construct a page that has links to relevant pages within the web site. Other sites provide a menu of topics from which to select and perform a search. Either way, remember that these types of searches are performed within a site, not across all Web sites.

Is there a quick way to go to a search engine without having to memorize a URL address?

Here are two quick ways to get to a search engine when you need one:

1. If you have Netscape Navigator or Internet Explorer, click on your "Search" button on your browser bar at the top of your screen. This will take you to some pre-set search engines.
2. Make Bookmarks/Favorites of all the search engines, that way if one is very busy you can skip over to the next engine.

MISCELLANEOUS INFORMATION

What does it mean when I click on a link and get a "File Not Found" message?

This error message indicates that your computer was unable to locate a web page at that particular URL (web address). Some common reasons for this error message are:

- the web page's URL was changed
- web page's URL was incorrectly listed by the linked page
- the web page no longer exists
- the server holding this URL is temporarily out of commission

Remember that the Internet is in a state of constant change. Web sites come and go, many sites relocate without telling anyone, and dead listings are everywhere. Remember to use more than one search engine when trying to find a page that may have been moved.

How can I see more of a web page on my screen?

If the window in which you're viewing a web page is not expanded to the full width of the screen, you may want to "maximize the window." This way the designed pages will fill the entire width of the screen, and you will have less scrolling down to do as you read. Here's how:

For Windows:

Click on the middle box in the upper right hand corner of your screen. If the window is not maximized, the icon looks like a single window frame. After you click on it to maximize, it will change to two smaller frames, one in front of the other.

For a Macintosh:

Click on the box located in the upper right corner of the window (with a right angle in it).

In all cases, clicking on the same box will return the window to its original size. If the maximize button does not resize the window to fill the entire screen, there is a sizing handle in the lower right hand corner of the window. If you click and hold your mouse on this corner, you can drag the window to whatever width you desire.

Should I be concerned about my privacy on the Internet?

Like the real world, aspects of the Internet can pose danger and harm. And, like the real world, there are precautions you can take to protect yourself. The main thing to be aware of is that Internet sites may use or give to others any information you provide, without your permission.

Below are some tips to help you protect your privacy, anonymity and security on the Internet:

1. Never give personal information (such as your name, age, gender, address, or phone number) in e-mail messages, chat rooms, bulletin boards, newsgroups or listservers. Choose a screen name that does not reveal your identity, gender or location. Explore the privacy protections available through your Internet Service Provider (ISP).
2. Before giving financial information (such as your bank account or credit card number) to an on-line company, make certain that the Web site is authentic and that you understand their privacy, customer-service and refund policies. Reliable sites will provide an encryption system to protect your account security.
3. Protect your online password(s). Never tell your password to anyone online. No reliable company or service technician will ask for it. Many people change their passwords regularly. It's an easy way to protect your privacy online, particularly if you think someone has discovered or is using your current password.
4. Before submitting surveys and registration forms on the Internet, be sure you know why the site is collecting the information and what they are going to do with it.
5. Read the privacy policy of any site you visit.
6. Never give details about your plans to be out of the house or traveling to anyone.
7. Report any X-rated, threatening or hostile mail to your Internet Service Provider.

Where can I go for more advanced instruction on how to use the Internet?

For more advanced, step-by-step guides to exploring the Internet, using email, downloading files, participating in online chat rooms, and using bulletin boards, check out the following sites:

<http://www.newbie-u.com/>

<http://www.webnovice.com/faq.htm>

<http://www.larrysworld.com/primer.htm>

<http://www.learnthenet.com/english/index.html>

<http://www.educ.sfu.ca/tutorial/>

Appendix #4
Pre-Test Survey

CHES Project:
Comprehensive Health Enhancement Support System

PreTest

If you have any questions please contact:

*Fiona McTavish
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Center for Health Systems Research and Analysis
1124 WARF Building
610 Walnut Street
Madison, WI 53705*

1-800-361-5481 or 1-608-262-7852

Fmctavish@chsra.wisc.edu

Code Number: _____

For this research on different kinds of assistance for women facing breast cancer, we need to have some idea how you're doing now, before the study starts. Below is a list of things that other women with breast cancer have said. By checking one box per line, please indicate how true each statement is for you.

<i>At this time...</i>	Not at all	A little bit	Some- what	Quite a bit	Very much
1. There are people I could count on for emotional support.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
2. There are people I could rely on when I need help doing something.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
3. There are people who will help me evaluate things I'm finding out about my illness.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
4. I am pretty much all alone.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
5. There are people who can help me find out the answers to my questions.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
6. There are people who will fill in for me if I am unable to do something.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4

Below is a list of statements concerning how you're dealing with breast cancer. By checking one box per line, please indicate how much you agree/disagree with each statement during the past 7 days. [CHECK ONE BOX ON EACH LINE]

	Disagree very much	Disagree	Neither agree or disagree	Agree	Agree very much
7. I need more information about breast cancer from the perspective of patients who have been there.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
8. I need more understandable information about breast cancer.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
9. I need more information about the latest breast cancer research.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
10. I need more contact with people who understand what I am going through.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
11. I need help making decisions.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
12. I understand what my doctor told me.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
13. I am confident I can have a positive effect on my health.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
14. I have set some definite goals to improve my health.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
15. Generally, I have been able to meet the goals I set for myself to improve my health.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
16. I am actively working to improve my health.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
17. I feel that I am in control of how and what I learn about my health.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4

Below is a list of things that other women with breast cancer have said. By checking one box per line, please indicate how true each statement is for you.

At this time...

	Not at all	A little bit	Some- what	Quite a bit	Very much
18. I am able to work (including work in home).	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
19. My work (including work in home) is fulfilling.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
20. I am able to enjoy life "in the moment".	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
21. I am sleeping well.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
22. I am enjoying my usual leisure pursuits.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
23. I feel sad.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
24. I feel like my life is a failure.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
25. I feel nervous.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
26. I am worried about dying.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
27. I feel like everything is an effort.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
28. I am worried that my illness will get worse.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4

Please indicate how true each statement is for you. [CHECK ONE BOX ON EACH LINE]

During the past 7 days:

	Does not apply	Not at all	A little bit	Some- what	Quite a bit	Very much
29. I was short of breath.		<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
30. I was self-conscious about the way I dress.		<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
31. I was bothered by swollen or tender arms.		<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
32. I felt sexually attractive.		<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
33. I worried about the risk of cancer in other family members.	<input type="radio"/>	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
34. I worried about the effect of stress on my illness.		<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
35. My change in weight bothered me.	<input type="radio"/>	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
36. I was able to feel like a woman.		<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4

Thinking about your experiences since you've had breast cancer, how much do you agree or disagree with these statements? [CHECK ONE BOX ON EACH LINE]

	Disagree very much	Disagree	Neither Agree or Disagree	Agree	Agree very much
Since I've had breast cancer,					
37. Having information about my breast cancer, treatment, and prognosis gives me a sense of control.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
38. I prefer to have all the details (including possible risks) regarding my breast cancer and treatment options.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
39. I feel comfortable in asking the physician or nurse a lot of questions.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
40. I feel confident in making major decisions about my health.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
41. I can figure out how and where to get the information I need.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
42. I know what questions to ask my doctor.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
43. I am able to be assertive with my doctor.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
44. I trust my doctor.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4

How much do you agree or disagree with these statements? [CHECK ONE BOX ON EACH LINE]

	Disagree very much	Disagree	Neither Agree or Disagree	Agree	Agree very much
At this point I feel I understand:					
45. The effect my treatment will have on my quality of life.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
46. How to deal with breast cancer in my work and with my family.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
47. What my treatments will be like.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
48. The Pro's and Con's of various treatment approaches.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
49. How to know if a health care provider is good.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
50. How to get through my treatments and their side effects.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
51. How to get a second opinion if I want one.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4

Please tell us about yourself BEFORE you were diagnosed with breast cancer (even before you first noticed the symptom or had the test that raised the possibility of breast cancer). Try to remember how you were feeling then in answering the following question. . [CHECK ONE BOX]

52. In general, would you say you have been:
- ☐₁ Feeling normal with no complaints and able to carry on your usual activities.
 - ☐₂ Performing normal activities with some effort and minor signs of illness.
 - ☐₃ Unable to carry on your usual activities or do physical tasks. Requiring occasional assistance but in bed less than 50% of the daytime.
 - ☐₄ Disabled, requiring special care and assistance in most activities & in bed more than 50% of the daytime, but not all day.
 - ☐₅ Very sick, hospitalized for some time or in bed all of the time.

Appendix #5

2 Week Post-Test Survey

CHES Project:
Comprehensive Health Enhancement Support System

2 Week Post-Test

If you have any questions please contact:

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Madison, WI 53705*

1-800-361-5481 or 1-608-262-7852

Fmctavish@chsra.wisc.edu

Code Number: _____

TREATMENT DECISIONS

- 1 Please indicate if, during the **last two weeks**, you (and/or your doctors) **have considered whether or not** to have any of the following **treatments**. For each treatment you considered, please indicate in the space provided what you (and/or your doctors) eventually decided to do. If you are still considering a treatment and have not yet made a decision, please check the "don't know yet" box.

I considered (check all that apply):

- ☐₁ Fine needle biopsy
- ☐₂ Lumpectomy versus mastectomy
- ☐₃ What to radiate (axila)?
- ☐₄ Breast reconstruction
- ☐₅ Type of reconstruction
- ☐₆ Timing of reconstruction
- ☐₇ Lymph node sampling
- ☐₈ How many lymph nodes to sample
- ☐₉ Chemotherapy
- ☐₁₀ Type of chemotherapy
- ☐₁₁ Length of chemotherapy
- ☐₁₂ Bone marrow transplant
- ☐₁₃ Oophorectomy (ovary removal)
- ☐₁₄ Tamoxifen
- ☐₁₅ Clinical trial participation
- ☐₁₆ Immunotherapy
- ☐₁₇ Alternative treatments
- ☐₁₈ Stopping treatment
- ☐₁₉ Other, please specify: _____

I chose to:

- ☐ Don't know yet
- ☐ Don't know yet
- ☐ Don't know yet
- ☐ Don't know yet
- ☐ Don't know yet
- ☐ Don't know yet
- ☐ Don't know yet
- ☐ Don't know yet
- ☐ Don't know yet
- ☐ Don't know yet
- ☐ Don't know yet
- ☐ Don't know yet
- ☐ Don't know yet
- ☐ Don't know yet
- ☐ Don't know yet
- ☐ Don't know yet
- ☐ Don't know yet
- ☐ Don't know yet

If you did not check any decision at this time, please skip to page 3

- 2 If you **considered** more than one treatment decision above, please indicate which one was the **most difficult** to consider: _____
- 3 For the question below, please check the one box that best describes how you would like to make that decision:
- ☐₁ I prefer to make the decision about which treatment I will receive
- ☐₂ I prefer to make the final decision about my treatment after seriously considering my doctor's opinion
- ☐₃ I prefer that my doctor and I share responsibility for deciding which treatment is best for me.
- ☐₄ I prefer that my doctor make the final decision about which treatment will be used but seriously consider my opinion.
- ☐₅ I prefer to leave all decisions regarding treatment to my doctor.

Still thinking about that most difficult treatment decision you **considered**, please indicate how much you agree/disagree with the following statements.

	STRONGLY DISAGREE	DISAGREE	NEITHER AGREE NOR DISAGREE	AGREE	STRONGLY AGREE
4 It is difficult to make a choice.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
5 It's clear what choice is best for me.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
6 I'm aware of the choices I have in making this decision.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
7 I feel I know the relative benefits of my options for this decision.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
8 I feel I know the relative risks and side effects of my options for this decision.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
9 The information I have to make this decision is easy to understand.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
10 I have no problem using the information I have in making this decision.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
11 Consulting someone else would have been useful in making this decision.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
12 I am satisfied that I am adequately informed about the issues important to my decision.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
13 I need more advice and information about my options.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
14 I have access to information on all my options.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5

If you have **decided** what to do for this decision at this point, please indicate how much you agree/disagree with the following statements. Otherwise please skip to question 20.

15 My decision is sound.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
16 I am satisfied with my decision.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
17 My decision is the right one for my situation.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
18 I am satisfied that my decision was consistent with my personal values.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
19 I feel I have made an informed choice.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5

NON-TREATMENT DECISIONS

20 Please indicate whether you have **considered** any of the following decisions in the last two weeks

I considered (check all that apply):

- | | |
|---|--|
| <input type="checkbox"/> ₁ Whether to change doctors?
<input type="checkbox"/> ₂ Whether to seek second opinion?
<input type="checkbox"/> ₃ Who/what to tell family/friends/
children/co-workers?
<input type="checkbox"/> ₄ Who to be around?
<input type="checkbox"/> ₅ Whether to quit work/go back to work? | <input type="checkbox"/> ₆ Whether to go to a support group?
<input type="checkbox"/> ₇ Whether to quit smoking?
<input type="checkbox"/> ₈ Whether to leave my partner?
<input type="checkbox"/> ₉ End of life decisions?
<input type="checkbox"/> ₁₀ Other, please specify: _____ |
|---|--|

If you did not check any decision at this time, you can skip the remainder of the questionnaire. Please mail it back in the envelope provided.

21 If you considered more than one decision above, please indicate which one was the **most difficult** to consider: _____

Thinking about that most difficult decision you **considered**, please indicate how much you agree/disagree with the following statements.

	STRONGLY DISAGREE	DISAGREE	NEITHER AGREE NOR DISAGREE	AGREE	STRONGLY AGREE
22 It is difficult for me to make a choice.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
23 It's clear what choice is best for me.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
24 I'm aware of the choices I have in making this decision.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
25 I feel I know the relative benefits and risks of my options for this decision.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
26 Consulting someone else would be useful in making this decision.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
27 I am satisfied that I am adequately informed about the issues important to my decision.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
28 I need more advice and information about my options.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
29 I have access to information on all my options.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
30 I have the right amount of support from others in making this decision.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5

If you have **decided** what to do for this decision at this point, please indicate how much you agree/disagree with the following statements.

31 My decision is sound.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
32 I am satisfied with my decision.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
33 My decision is the right one for my situation.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
34 I am satisfied that my decision was consistent with my personal values.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
35 I feel I have made an informed choice.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5

Appendix #6
2 Month Post-Test Survey

CHES Project:
Comprehensive Health Enhancement Support System

2 Month Post-Test

If you have any questions please contact:

*Fiona McTavish
University of Wisconsin – Madison
Center for Health Systems Research and Analysis
1124 WARF Building
610 Walnut Street
Madison, WI 53705*

1-800-361-5481 or 1-608-262-7852

Fmctavish@chsra.wisc.edu

Code Number: _____

Coping with Breast Cancer. *The items below deal with ways you have been coping with the stress in your life since you found out you have breast cancer. Obviously different people deal with things in different ways, but we are interested in how you have tried to deal with it. How much or how frequently have you been doing what each item describes. . Don't answer on the basis of whether or not it seems to be working or not – just whether or you're doing it. Try to rate each item separately in your mind from the others. Make your answers as true for YOU as you can.*

In the past 2 weeks ...	I haven't been doing this at all	I've been doing this a little bit	I've been doing this a medium amount	I've been doing this a lot
1. I've been turning to work or other activities to take my mind off things.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
2. I've been trying see it in a different light, to make it seem more positive	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
3. I've been criticizing myself	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
4. I've been looking for something good in what is happening	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
5. I've been making jokes about it	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
6. I've been doing something to think about it less, such as going to movies, watching TV, reading, daydreaming, sleeping, or shopping	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
7. I've been trying to find comfort in my religion or spiritual beliefs	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
8. I've been blaming myself for things that happened	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
9. I've been praying or meditating	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
10. I've been making fun of the situation	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
11. I have been helping other women newly diagnosed with breast cancer	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
12. I have been inspired by other women who have had breast cancer	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4

Info (and other) needs and health self-efficacy.

Below is a list of statements concerning how you're dealing with breast cancer. By checking one box per line, please indicate how much you agree/disagree with each statement during the past 7 days.

[CHECK ONE BOX ON EACH LINE]

	Disagree very much	Disagree	Neither agree or disagree	Agree	Agree very much
13. I need more information about breast cancer from the perspective of patients who have been there.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
14. I need more understandable information about breast cancer.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
15. I need more information about the latest breast cancer research.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
16. I need more contact with people who understand what I am going through.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
17. I need help making decisions.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
18. I understand what my doctor told me.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
19. I am confident I can have a positive effect on my health.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
20. I have set some definite goals to improve my health.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
21. Generally, I have been able to meet the goals I set for myself to improve my health.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
22. I am actively working to improve my health.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
23. I feel that I am in control of how and what I learn about my health.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4

Knowledge and Understanding

How much do you agree or disagree with these statements? [CHECK ONE BOX ON EACH LINE]

At this point I feel I understand:

	Disagree very much	Disagree	Neither Agree or Disagree	Agree	Agree very much
24. The effect my treatment will have on my quality of life.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
25. How to deal with breast cancer in my work and with my family.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
26. What my treatments will be like.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
27. The Pro's and Con's of various treatment approaches.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
28. How to know if a health care provider is good.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
29. How to get through my treatments and their side effects.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
30. How to get a second opinion if I want one.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4

Support

For this research on different kinds of assistance for women facing breast cancer, we need to have some idea how you're doing now. Below is a list of things that other women with breast cancer have said. By checking one box per line, please indicate how true each statement is for you.

<i>At this time...</i>	Not at all	A little bit	Some- what	Quite a bit	Very much
31 There are people I could count on for emotional support.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
32 There are people I could rely on when I need help doing something.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
33 There are people who will help me evaluate things I'm finding out about my illness.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
34 I am pretty much all alone.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
35 There are people who can help me find out the answers to my questions.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
36 There are people who will fill in for me if I am unable to do something.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4

Functional and Emotional well being

Below is a list of things that other women with breast cancer have said. By checking one box per line, please indicate how true each statement is for you.

<i>At this time...</i>	Not at all	A little bit	Some- what	Quite a bit	Very much
37. I am able to work (including work in home).	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
38. My work (including work in home) is fulfilling.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
39. I am able to enjoy life "in the moment".	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
40. I am sleeping well.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
41. I am enjoying my usual leisure pursuits.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
42. I feel sad.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
43. I feel like my life is a failure.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
44. I feel nervous.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
45. I am worried about dying.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
46. I feel like everything is an effort.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
47. I am worried that my illness will get worse.	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4

ADDITIONAL CONCERNS BECAUSE OF MY BREAST CANCER

By checking one box per line, please indicate how true each statement is for you.

During the past 7 days:

	Not at all	A little bit	Some- what	Quite a bit	Very much	Does not apply
48 I was short of breath	<input type="checkbox"/> ₀	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	
49 I was self-conscious about the way I dress	<input type="checkbox"/> ₀	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	
50 I was bothered by swollen or tender arms	<input type="checkbox"/> ₀	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	
51 I felt sexually attractive	<input type="checkbox"/> ₀	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	
52 My hair loss bothered me	<input type="checkbox"/> ₀	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅
53 I worried about the risk of cancer in other family members	<input type="checkbox"/> ₀	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅
54 I worried about the effect of stress on my illness	<input type="checkbox"/> ₀	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	
55 My change in weight bothered me	<input type="checkbox"/> ₀	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅
56 I am able to feel like a woman	<input type="checkbox"/> ₀	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	

Health care participation and relations with medical professionals.

Thinking about your experiences since you've had breast cancer, how much do you agree or disagree with these statements? [CHECK ONE BOX ON EACH LINE]

	Disagree very much	Disagree	Neither Agree or Disagree	Agree	Agree very much
Since I've had breast cancer,					
57. Having information about my breast cancer, treatment, and prognosis gives me a sense of control.	<input type="checkbox"/> ₀	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
58. I prefer to have all the details (including possible risks) regarding my breast cancer and treatment options.	<input type="checkbox"/> ₀	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
59. I feel comfortable in asking the physician or nurse a lot of questions.	<input type="checkbox"/> ₀	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
60. I feel confident in making major decisions about my health.	<input type="checkbox"/> ₀	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
61. I can figure out how and where to get the information I need.	<input type="checkbox"/> ₀	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
62. I know what questions to ask my doctor.	<input type="checkbox"/> ₀	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
63. I am able to be assertive with my doctor.	<input type="checkbox"/> ₀	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
64. I trust my doctor.	<input type="checkbox"/> ₀	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄

Karnofsky

For the question below, please check the box which best describes how you have been feeling in the last week. In general, would you say you have been:

- ☐₁ Feeling normal with no complaints and able to carry on your usual activities
- ☐₂ Performing normal activities with some effort and minor signs of illness
- ☐₃ Unable to carry on your usual activities or do physical tasks. Requiring occasional assistance but in bed less than 50% of the daytime
- ☐₄ Disabled, requiring special care and assistance in most activities and in bed more than 50% of the daytime, but not all day
- ☐₅ Very sick, hospitalized for some time or in bed all of the time

RESOURCES USE AND USEFULNESS

Breast cancer patients have indicated that it is important to:

- obtain information about breast cancer,
- have help in making decisions about breast cancer, and
- have support from others

Patients use a variety of resources to learn about, decide about, and deal with breast cancer. These resources can be broadly divided in six main types:

- A. Books, articles
- B. Audio or videotapes
- C. Clinicians (doctors and nurses)
- D. Family or friends
- E. CHES Computer System
- F. Computers (programs/software, Internet/World Wide Web)

INFORMATION

Thinking about the different resources you used in the last two months, please rate the usefulness of the different resources in obtaining good information about breast cancer.

65. Please rate how EASY it was for you to ACCESS information from each of the three types of resources:

	VERY DIFFICULT	DIFFICULT	NEITHER EASY NOR DIFFICULT	EASY	VERY EASY
A Books, articles	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
B Audio or videotapes	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
C Clinicians (doctors and nurses)	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
D Family or friends	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
E CHES Computer System	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
F Computers (programs/software, Internet/World Wide Web)	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5

66. Please rate how **MUCH information you USED** from each type of resource:

	VERY LITTLE	LITTLE	SOME	A LOT	A GREAT DEAL
A Books, articles	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
B Audio or videotapes	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
C Clinicians (doctors and nurses)	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
D Family or friends	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
E CHESS Computer System	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
F Computers (programs/software, Internet/World Wide Web)	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5

67. Please rate how **RELEVANT the information you got** from each type of resource was to you personally:

	VERY IRRELEVANT	IRRELEVANT	NEITHER RELEVANT NOR IRRELEVANT	RELEVANT	VERY RELEVANT
A Books, articles	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
B Audio or videotapes	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
C Clinicians (doctors and nurses)	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
D Family or friends	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
E CHESS Computer System	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
F Computers (programs/software, Internet/World Wide Web)	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5

HELP IN MAKING DECISIONS

Thinking about the different **resources** you used in the last two months, we would like you to rate the usefulness of the different types in **helping you make decisions** about breast cancer.

68. Please rate how **EASY it was for you to GET HELP in making decisions** from each type of resource:

	VERY DIFFICULT	DIFFICULT	NEITHER EASY NOR DIFFICULT	EASY	VERY EASY
A Books, articles	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
B Audio or videotapes	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
C Clinicians (doctors and nurses)	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
D Family or friends	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
E CHESS Computer System	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
F Computers (programs/software, Internet/World Wide Web)	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5

69. Please rate how **MUCH HELP in making decisions** you got from each type of resource:

	VERY LITTLE	LITTLE	SOME	A LOT	A GREAT DEAL
A Books, articles	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
B Audio or videotapes	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
C Clinicians (doctors and nurses)	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
D Family or friends	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
E CHESS Computer System	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
F Computers (programs/software, Internet/World Wide Web)	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5

70. Please rate how **EFFECTIVE** each type of resource was in **helping you make decisions**:

	VERY INEFFECTIVE	INEFFECTIVE	NEITHER EFFECTIVE NOR INEFFECTIVE	EFFECTIVE	VERY EFFECTIVE
A Books, articles	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
B Audio or videotapes	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
C Clinicians (doctors and nurses)	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
D Family or friends	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
E CHES Computer System	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
F Computers (programs/software, Internet/World Wide Web)	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5

SUPPORT FROM OTHERS

Thinking about the different **resources** you used in the last two months, we would like you to rate the usefulness of the different types in **having support to cope** with breast cancer.

71. Please rate how **EASY it was for you to GET SUPPORT from others** with each of the following two types of resources:

	VERY DIFFICULT	DIFFICULT	NEITHER EASY NOR DIFFICULT	EASY	VERY EASY
A Clinicians (doctors and nurses)	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
B Family or friends	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
C CHES Computer System	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
D Computers (programs/software, Internet/World Wide Web)	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5

72. Please rate how **MUCH SUPPORT you got for dealing with breast cancer** from each resource:

	VERY LITTLE	LITTLE	SOME	A LOT	A GREAT DEAL
A Clinicians (doctors and nurses)	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
B Family or friends	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
C CHES Computer System	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
D Computers (programs/software, Internet/World Wide Web)	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5

73. Please rate how **EFFECTIVE** each type of resource was in **giving you SUPPORT**:

	VERY INEFFECTIVE	INEFFECTIVE	NEITHER EFFECTIVE NOR INEFFECTIVE	EFFECTIVE	VERY EFFECTIVE
A Clinicians (doctors and nurses)	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
B Family or friends	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
C CHES Computer System	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
D Computers (programs/software, Internet/World Wide Web)	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5

BREAST CANCER HISTORY

74. When was your breast cancer first diagnosed (give approximate date): _____
75. Has your breast cancer spread (metastasized) to other parts of your body other than your lymph nodes?
☐₀ No
☐₁ Yes, when did you learn this (give approximate date): _____
76. Have you had a recurrence of your breast cancer?
☐₀ No
☐₁ Yes, when did you learn this (give approximate date): _____
77. Write in the actual or scheduled dates for surgeries that you have completed, and those that you have scheduled. Then mark any other surgeries you are considering.

	Date (give approximate date):	Considering
Radical mastectomy	_____	<input type="checkbox"/>
Modified radical mastectomy	_____	<input type="checkbox"/>
Lumpectomy	_____	<input type="checkbox"/>
Breast reconstruction	_____	<input type="checkbox"/>
Oophorectomy (ovary removal)	_____	<input type="checkbox"/>
Prophylactic (preventive) mastectomy of unaffected breast	_____	<input type="checkbox"/>
Other	_____	<input type="checkbox"/>

78. For each of the following breast cancer treatments, give the approximate starting and ending dates, or mark the box if you are seriously considering it. Give dates if you have done it, are doing it, or are planning a treatment.

	Start Date	End Date	Considering
Chemotherapy	_____	_____	<input type="checkbox"/>
Radiation	_____	_____	<input type="checkbox"/>
Hormone therapy (e.g., Tamoxifen, Halotestin)	_____	_____	<input type="checkbox"/>
High-dose chemotherapy & bone marrow transplant	_____	_____	<input type="checkbox"/>
Other: _____	_____	_____	<input type="checkbox"/>

79. In addition to your prescribed treatments, what else are you doing for your breast cancer (diet, homeopathy, acupuncture, therapeutic touch, etc.)? Please list below:

BACKGROUND & LIFESTYLE

80 Today's date: _____

81 What type of health insurance coverage do you have (include coverage obtained through a spouse or relative)?

- ☐₁ Private group insurance (through you/spouse's employer, union or trade group)
- ☐₂ Individual policy
- ☐₃ Medicaid (also called Title 19 or Medical Assistance)
- ☐₄ Medicare, Part A (pays for hospital bills)
- ☐₅ Medicare, Part B (pays for doctor's bills)
- ☐₆ Medigap policy (supplementary private insurance to Medicare)
- ☐₇ CHAMPUS or CHAMPVA
- ☐₈ Other: _____
- ☐₉ No insurance

82 With whom do you currently live [CHECK ALL THAT APPLY]?

- ☐₁ I live by myself
- ☐₂ I live with my partner (husband, lover)
- ☐₃ I live with one or more dependent children ,
Please list ages and sex of dependent children _____
- ☐₄ I live with one or both of my parents
- ☐₅ I live with other family members
- ☐₆ I live with a friend or friends
- ☐₇ Other, please specify _____

Appendix # 7

DOD - Study Protocol

Protocol for DOD Study:

- **Recruitment**
- **CHES/Internet Installation and Demonstration**

RECRUITMENT;

Introduction by the Physician and the Nurse

Both the physician and the nurse play an important role in the recruitment of patients. Their support and enthusiasm is crucial. They are the first people to introduce the patient to the idea of being involved in the study. Their support reassures the patient that the study is valid and worthwhile. The site coordinator can then build on the positive base which the doctor and nurse have begun to establish. Even though the doctor and nurse do very little explanation of the study, their endorsement is crucial in getting patients involved.

Patient Introduction to Research Study by the Physician:

All women 18 years or older diagnosed with breast cancer within two months at the University of Wisconsin Comprehensive Cancer Center, UW Milwaukee School of Nursing and Mayo Clinic in Rochester MN will be asked to join the research study except for those who: 1) are homeless; or 2) cannot read and understand sample questions from the pre-test survey.

They will be asked at their first appointment at the clinic. The attending physician will be the first person to introduce the research study to the patient. The physician will briefly discuss the importance of research in general and more specifically why he/she endorses this study. The physician will mention that the site coordinator will explain the study to the patient and answer any of their questions.

Suggested Introduction of Study by Attending Physician to Patient:

"We presently have a research study taking place which you may be interested in joining. The study is about information and support patients receive. The only way that we can find out what sort of information and support is most helpful to patients diagnosed with breast cancer is through studies like this. I'll have the nurse introduce you to the site coordinator of the research study before the end of your visit today. I hope you'll consider participating in this study. "

Nurse's Interaction with Patient Regarding Study:

The nurse will encourage the patient to participate in the research study that the attending physician briefly discussed with her. The nurse should screen out any patients known to be homeless or illiterate, under 18 years of age or more than 2 months past initial treatment for breast cancer, letting the patient know that the study is not appropriate for them. The nurse will discuss that the cancer clinic (or hospital) is excited to be a part of this study because it is first and foremost beneficial to the patient. At this point she will introduce the site coordinator to the patient. The site coordinator will describe the study in more detail and answer any questions the patient may have.

Suggested Introduction of Study Coordinator by the Nurse:

"I'd like to introduce _____ (site coordinator's name). She is the site coordinator for the research project which Dr. _____ briefly described to you. The purpose of the study is to see what sort of support and information is most helpful to patients. We are fortunate to be one of three sites that are taking part in this study. The project is funded by the Department of Defense. I'll let _____ (site coordinator's name) tell you more about the research study and how you can get involved. She'll be able to answer any of your questions. I'll be back in a few minutes to see about scheduling your next appointment with Dr. _____."

The Site Coordinator / Study Introduction:

The site coordinator plays an important role in making the patient feel comfortable in the midst of hearing very difficult news. Site coordinators are chosen for their sensitivity to people in crises, their belief in research, and their excitement for the CHESS project. (To date, we have had very effective results in breast cancer patients accepting CHESS upon diagnosis, with approximately an 80% acceptance rate).

The site coordinator begins by reintroducing themselves to the patient and acknowledging the fact that this is a very difficult time for the patient. They go on to explain why the research project is important, what the research project entails, including the benefits to the patient as well as benefits to future patients and research in general. It is important to build a sense of trust with the patient quickly.

Suggested Explanation of Project to the Patient by the Study Coordinator:

"As _____ (the nurse's name) mentioned, I'm _____ (your name), the site coordinator for a research project funded by the Department of Defense. I realize this is a difficult time for you and in some ways I feel awkward bringing up a research project in the midst of this. However I'm committed to this project because I believe it will benefit you as well as other patients in the end."

"All patients who are within two months of initial treatment for breast cancer are eligible for the study, except for those who are homeless and those who cannot read or those who are less than 18 years of age. Do you fall into any of these categories? I don't need to know which one."

If patient answers yes, say "Thank you, but I'm afraid this study won't be appropriate for you. Thank you for your time. I'll let the nurse know that you are waiting for her."

If patient answers no, explain the study to the patient.

Explanation of the DOD study:

"We are trying to see what kind of information and support is most helpful to patients diagnosed with breast cancer. The study has four groups. All of the groups will receive information about breast cancer, but they will get the information in different ways. The first group will get a set of audio tapes called *The Cancer Survivor's Toolbox*. Tape players will be available for those patients who need them. The second group will receive any or all of the following books: Dr. Susan Love's Breast Book, written specifically for women with breast cancer; Breast Cancer? Let Me Check My Schedule, a book written about the experiences of ten professional women who all experienced breast cancer; and Celebrate Life, a book that highlights about 40 stories of African American women dealing with breast cancer.

The third and fourth groups will get information about breast cancer by having a computer placed in their home for five months. One of the groups will get a computer program called CHESS. CHESS stands for the Comprehensive Health Enhancement Support System. CHESS has a variety of services in it, including up to date information about breast cancer and the ability to be connected to other women who have breast cancer. Also, since CHESS uses the Internet, you will also receive free Internet access as well. The other group will get a computer that only has Internet access. Both services will be provided at no cost to you.

No computer experience is necessary to be a part of this study. We will provide training on both systems. The computer will be in your home for 5 months. There is no cost to you! Again, don't worry if you know nothing about computers, **absolutely no computer experience is needed.**

I cannot guarantee which group you will be in as people are randomly placed in one group or the other. If you are in a group that gets a computer, I can set up a time with you in the next several days to bring the computer to your home and show you how it works. Each participant who gets the computer is given a code name to ensure their anonymity. As I mentioned to you earlier, this would not cost you anything. Since the computers are laptops, the only thing you will need to have at home is an electrical outlet to provide power to the computer and a phone jack in order to connect to the Internet.

Each person agreeing to be in the study regardless of which group they are in will need to fill out a total of seven surveys. You will be reimbursed for every survey you fill out. The first one will be filled out now, and the rest of the surveys will be mailed to you. There are three short surveys which will take about ten minutes each. You will get \$5 per survey for filling those out. The others are longer and will take about 20-30 minutes to fill out. You will get \$15 for each of the longer surveys. You will be reimbursed a total of \$75 over the course of the study. It is very important that you complete the surveys and send them back in the self addressed envelope as soon as possible. Other than filling out these surveys however you have no further responsibilities to this study. Also, your survey answers remain anonymous. If you decide to participate in the study, you are assigned a number, which is the only identification on any data we collect. I will be the only person who has both your name and number other than the project director. This information will not be accessible to anyone else. It will be kept in a locked file drawer in my office.

This research study will not affect the treatment you receive in anyway. Your doctor will not know whether or not you agreed to be in the study. There is absolutely no cost to be involved in this study, in fact, as mentioned earlier you would gain a total of \$75.00 just by filling out the surveys.

Just as you benefit from taking part in this study we benefit also. We get your feedback on what information is most helpful to patients. This helps us to develop material that meets the needs of patients. Without your input we can't do this nearly as effectively.

Would you be willing to be part of this research study?"

If the patient says yes, they would like to be in the study, be sure to ask them whether they are pre-treatment or post-treatment. This will be important for randomization.

RECRUITMENT, Patients Responses, What Next?

- **NEGATIVE RESPONSE:**

Ask them if they would be willing to answer some questions of why they decided not to be in the study. Verbally go over the "Declined To Be In Study" sheet with them.

Be sure to thank them for their time.

- **POSITIVE RESPONSE:**

Thank them for their willingness to participate in this study. Go over the consent form with them and if they are willing to sign it now, have them sign the duplicate page of the consent form. you will also need to sign the form. Give them the entire consent form. Be sure to keep the duplicate page, which they have signed. Take the next randomized envelope out of the package once you have a signed consent form. Fill out the Study Participant Tracking form, which includes basic information, such as names, phone number(s), address... Note -- Only put down their work phone number if it is okay to call them there. The Id # on this form will be the number on the randomized envelope. Next, give them the Pre-Test survey to fill out. Be sure to mark the id # on the survey. Ask the study participant to fill out the survey and when she is finished to put it in the brown manila envelope and seal it (again the pre-assigned control number must appear on the survey prior to giving it to the participant to fill out).

Let her know that you will be outside while she fills out the survey. Also let her know that when the nurse returns to schedule her follow up appointment you will pick up the survey. At that time you will let them know which group they are in. **Note** – a study participant can not be randomized until they have returned their completed PreTest.

RANDOM ASSIGNMENT:

Once the pre-test is returned, the subject will be randomly assigned to one of the groups. Each site will have two sets of envelopes, which contain a randomly generated assignment to the study groups. One set of envelopes is for women who are pre-treatment, the other for women who are post-treatment. Pre-treatment is defined as any women who has not had treatment for her breast cancer such as surgery or chemotherapy. If she has had a biopsy, but has not had any further surgery, she would be considered pre-treatment.

The randomization envelopes are in numerical order and must be opened in order. The number on the envelope will be the person's code (or id #) number. Open an envelope from the appropriate set (pre or post treatment) to determine which of the following groups the research participant will be assigned. Mark this information on the tracking sheet, which you have for the participant. If she is in a group that gets a computer, when you inform her of which group she is in, schedule a training time with her. If she is in the group that gets the audio cassettes, offer her a tape player. If she is in the control group, give her any or all of the following books: Dr. Susan Love's Breast Book; Breast Cancer? Let Me Check My Schedule; and Celebrate Life. No matter which group she is in let her know you will call her in a week to see how she is doing.

A: Control Group:

If she is assigned to the Control Group (the group that gets the books) the site coordinator will give the study participant a copy of any or all of the following books: Dr. Susan Love's Breast Book; Breast Cancer? Let Me Check My Schedule; and Celebrate Life, along with your phone number in case she has any questions. The site coordinator will also call the study participant one week from their agreeing to participate in the study to see how she is doing and answer any questions she may have about the study.

The site coordinator should also let the study participant know that she will receive \$15 for completing the pre-test survey within two weeks. Mention that the next survey will come in the mail in two weeks, and that the next few surveys will come at two-week intervals so there will be quick turn around time between filling out the surveys and getting the next one. The name of the study participant should not appear on the survey or on the return envelope.

The recruiter must send the information from the tracking sheet to Fiona (the project director in Madison) by email or fax (Fmctavish@chsra.wisc.edu; FAX: 608.263.4523; Voice: 608.262.7852). This will let Fiona know that participant # _____ needs to be reimbursed for the pre-test. If the participant does not receive a reimbursement within four weeks, she should contact the site coordinator who will look into the matter.

B. Audio Cassette Group:

If the study participant is assigned to the Audio Cassette group, the site coordinator should offer her a tape player along with the audio cassettes.

Like the other study participants, the experimental group will receive a phone call from the site coordinator one week after joining the study to make sure they are doing okay.

The site coordinator should also let the study participant know that she will receive \$15 for completing the pre-test survey within two weeks. Mention that the next survey will come in the mail in two weeks. The name of the study participant should not appear on the survey or on the return envelope.

The recruiter must send the information from the tracking sheet to Fiona (the project director in Madison) by email or fax (Fmctavish@chsr.wisc.edu; FAX: 608.263.4523; Voice: 608.262.7852). This will let Fiona know that participant # _____ needs to be reimbursed for the pre-test. If the participant does not receive a reimbursement within four weeks, she should contact the site coordinator who will look into the matter.

C. Computer Groups:

If the study participant is assigned to one of the groups that get a computer the site coordinator will set up an appointment to take a computer to the participants home. The training will take about an hour. Ask for directions to her home and be sure to have the phone number and address on the tracking sheet. The computer should be installed within 72 hours, if at all possible – and if it is convenient for the study participant. The site coordinator will need to set up the Internet connection before the computer can be used in the home.

The research project will pay for the Internet connection for the five months that the computer is in the home. When the computer is removed from her home (5 months after installation), the Internet connection will be disconnected unless the participant elects to keep the connection and takes full responsibility for all costs incurred.

Like the other study participants, the computer group will receive a phone call from the site coordinator one week after joining the study to make sure they are doing okay. This also allows the site coordinator to answer any questions the participant may have regarding the study in general or questions they may have regarding the computer.

The site coordinator should also let the study participant know that she will receive \$15 for completing the pre-test survey in approximately two weeks. Mention that the next survey will come in the mail in two weeks. The name of the study participant should not appear on the survey or on the return envelope.

The recruiter must send the information from the tracking sheet to Fiona (the project director in Madison) by email or fax (Fmctavish@chsra.wisc.edu; FAX: 608.263.4523; Voice: 608.262.7852). This will let Fiona know that participant # _____ needs to be reimbursed for the pre-test. If the participant does not receive a reimbursement within four weeks, she should contact the site coordinator who will look into the matter.

Site Coordinator Protocol for Interaction with Study Participants:

The site coordinator will call all research participants (regardless of which group they are in, experimental or control) one week after initially joining the research study to see how she is doing and ask if she has any questions regarding the study.

General Phone Call Etiquette:

- Introduce yourself and remind the study participant that you are the research site coordinator that they met at the hospital.
- Ask if this is a good time to talk or should you call them back at a later time?
- Ask how they are doing, feeling ...
- Ask them if they have any questions regarding the study.
- If the phone call is regarding post-test surveys, ask the participant if they received the survey, and remind them to fill it out and return it as soon as possible.
- Thank them for their time and let them know they can call you if they have any questions.

UW Madison Phone Calls

The UW Madison will call all research participants three days after sending out the two, four and six week surveys. The purpose of this phone call is to be sure that they received the survey and to remind them to complete it and send it back in the pre-addressed envelope. The site coordinator should call the participants one-week after sending out the two-month, four-month and nine-month post-tests. If the post-test survey is not returned within a week, a second phone call will be made and a second survey will be mailed out if necessary. If the survey is still not returned within another week, the site coordinator will try to collect the data by phone interview.

Installation Protocol:

The site coordinator will install computers in the patient's home. The following is an outline of the installation process, followed by an outline of how to walk a person through CHES and/or the Internet for the first time.

Computer Installation: Phone call to Arrange Installation Time – if not arranged at time of recruitment:

- 1. Re-Introduction**
 - a. Name
 - b. Connected with UW Milwaukee School of Nursing, CHES Research Project funded by DOD
- 2. Hardware Requirements**
 - a. Electrical Outlet
 - b. Phone Jack
- 3. Information Installer Needs**
 - a. Rotary or Touch-tone Phone lines
 - b. Call Waiting? Y/N
 - c. Is it long distance to the city where the Internet provider is located? Y/N
 - d. Ask the user to choose a codename and password. Explain to them that each time they use CHES they will need these codes to "log in." These also assure the user of anonymity. Suggest that they write these codes down on a piece of paper and put them in a safe place so they have them in case they forget them.
 - e. Time and Date to install computer
 - f. Explain that installation usually takes about an hour
 - g. Directions to house if installation will be done in the home
 - h. Complete address (zip code and phone number and correct spelling of name.)
- 4. Restate date and time of Computer Installation**

CHES: Pre-Installation Checklist for Installer

1. CHECKLIST

- ☐ Call Fiona in Madison to set up Internet connection.
- ☐ Enter the codename and password of the person before the installation date. To do this, go to <http://chess.chsra.wisc.edu/admin/>. This will take you to the Remote Administrative Tools section.
 1. Login using codename: DOD and password: Thistle.
 2. Select Add a New User.
 3. Make sure Use Experts in: Madison – CIS is chosen
 4. CHES Expert: Always mark: No
 5. Group Facilitator: Always mark: No
 6. User is:
 - Patient
 - Support (Spouse, Partner, Child)
 - CHES Staff
 - No Discussion Group or Ask an Expert
 - No CHES Access
 - If the person gets Internet Only, choose No CHES Access
 - If the person gets CHES – choose, Patient
 - If a spouse or family member wants to use CHES, they must have a different codename and password – and then choose Support
 7. Choose the discussion groups the woman will be allowed to use if she was randomized to CHES.

CHES: Computer Installation

1. Equipment to Take:

- 2 laptops with carrying cases
- 1 power cord for the laptop
- 1 Telephone line cord
- Telephone cord extension adapter
- Telephone line adapter (splitter)
- mouse

2. Misc. Items to Take:

- CHES Breast Cancer Manual (Every participant will receive "How to Use the Internet" and depending if they are in the CHES group, they would receive "How to Use CHES" and the Quick Reference Sheet
- For the patients who receive Internet only, bring the pamphlet with good breast cancer sites on the Web to leave with them.
- Telephone number, address and directions to participant's home
- Help Line phone number (1-800-480-9223) in case there are any problems
- Map of the area

3. Setting Up the Computer

- a. Ask where computer can be placed
- b. Find telephone jack
- c. Find electrical outlet
- d. Set up computer (This should take about 5 minutes)

**Always take an extra Laptop with you
just in case there is any trouble with the original one.**

**Be sure you are comfortable with setting up
computers before taking one out to install!**

1. WALKING THE PERSON THROUGH CHESS AND/OR THE INTERNET

(This should take 50 to 60 minutes. If other family members are there and want to be involved it will take approximately 10 more minutes).

- a. **Reassure** the person that no computer experience is necessary and that everything you will be telling them is in the instruction manual, quick reference sheet and on the computer screen. They can also call you or the Help Line (1-800-480-9223) if they have any questions.
- b. **Turning on the computer**
Use the power switch on the laptop to turn the computer on.
- c. **Describe the keyboard and mouse** to the user. Explain to them that while there is a finger mouse provided on the laptop, we will also give them a separate mouse which may be easier for them to use. ****Remember that the mouse needs to be plugged in prior to turning on the computer.** Have the user sit down at the computer and use the keyboard and mouse as you walk them through CHESS. If they have never used a mouse before, let them use it to get a feel for how it works before you begin.
- d. **Show her how to log on to CHESS** using YOUR code name and password. You will log on to CHESS using the code name and password you put in for them at the end of the session.

2. TRAINING FOR THOSE WHO RECEIVE CHESS WITH INTERNET ACCESS:

To begin training, click on the CHESS icon on the desktop. The CHESS Start page will come up. Using the CHESS site, begin the training by going over some basic Internet skills. **Sign on with your own password to begin training.**

- a. **Explain** the navigation functions of the browser:
 - **Back/Forward Button**
The BACK and FORWARD buttons are located on the browser toolbar at the left hand side of the screen. The BACK button allows the user to jump back to the previous screen you were viewing. The FORWARD button allows them to move forward in the same way.
 - **Scroll Bar**
Show the user how to move the screen up or down by either clicking on the bar with the left hand mouse button and dragging the mouse up or down or by using the arrows at the top or bottom of the screen.
 - **Home**
Explain to the user that this will always bring them back to the CHESS Home Page.
- b. **Highlight** the fact that when the cursor moves over a link, it changes from an arrow to a hand. This will help the user find links when they are in the form of pictures or other graphics.
- c. **Show** the user the way that a hyperlink changes color when they have already visited it.
- d. **Show** the user how to use the mouse and click into a search box in order to begin typing the words for the search.
- e. **Demonstrate** how to use the search engine Alta Vista (www.altavista.com). Use the help section provided on the page to show the user different ways to search and then try searching for something they are interested in. A suggestion would be to have them search for "dogs", and then, to narrow the search, search for "police dogs." This will give them an idea of how many entries will can come up for a general topic, as well as how to narrow their search topic.

Next, move on to the CHESS specific navigation of the **Tool Bar**. After the explanation of each section, click on the word to give the user an idea of what happens in each section of the Tool Bar:

- a. **Topics** This section allows you to search CHESS by specific topics such as menopause, emotional support, and pain. You can click on a word and select a topic you are interested in finding out about.
- b. **Dictionary** CHESS has a dictionary of words that are medical and/or technical in nature that relate to breast cancer. By clicking on the Dictionary button on the toolbar, you can find the meaning of words you may not be familiar with.
- c. **Bookmarks** This section of CHESS allows you to "mark your place" and

come back to information you may be particularly interested in.

d. Keywords

To search for a specific topic by keyword such as menopause, emotional support and pain, click the Keyword button on the toolbar. The keywords are organized using the alphabet. You can click on a letter to see the list of keywords that begin with that letter. To search for a specific keyword, type the word into the search box provided. You can get a complete list of the keywords by pressing the search button without typing anything in the box.

e. Help

You can click on the Help button no matter where you are in CHESS and helpful information for that particular part of the website will come up.

3. EXPLAINING THE CHESS SERVICES:

Using the words Main Menu at the left hand side of the screen, take the user back to the Main Menu. From here, explain the services provided on the website. The following list is **IIMPERATIVE** to go over in detail with the participant. The other services can be touched on verbally in the course of the training session.

a. Overview of Breast Cancer

This section is provided to help women who have been recently diagnosed with breast cancer and who are just beginning the search for information about the disease. It contains basic information about breast cancer and the treatment options available.

Click into Overview of Breast Cancer and click on the first link in the list, Breast Cancer Basics. Explain to the participant that they can read the short paragraph provided and then look at condensed lists of information taken from Questions and Answers, Instant Library and Personal Stories that relate to the basics of breast cancer. The other two sections are set up in the same way.

b. Questions and Answers

Questions and Answers provide answers to the most commonly asked questions by women with breast cancer, their partners, and family. There are about 500 questions in the breast cancer module.

The user can look up questions through topics, such as diagnosis, treatments, prevention, emotions..., or they can use the Search function and type in a word they are interested in knowing more about. The search will bring up a list of questions that include that particular word. Ask the woman to whom you are demonstrating CHESS to click on the link to Questions and Answers.

Have the woman click on the word "Treatments." This brings up another list of options, from which she should choose "Surgery", and then "Questions to Ask Before Surgery". Have her choose the question "What questions should I ask Before Surgery?" and let her read the answer.

At the bottom of the page, there is a list of keywords. Explain that she can click on a keyword to get more information relating to the topic of the question. Have her choose the keyword, Doctors, Communication With. A box will appear telling the user which CHESS services have information on this topic. Click on the button for Instant Library. The computer will immediately link to an in-depth article related to that topic. Once the user has finished reading the article she can go to other CHESS Services that have information on that same topic or return to Questions and Answers. Return to the Services page by having the user click on the Services link on the top left of the screen.

c. Web Links

Next take the user to the Web Links section from the Services page. Explain to the user that Web Links is a list of web sites that the developers of CHESS have reviewed for content and reliability.

Click on Web Links and a list of web sites will come up. Have the user click on American Cancer Society. This will take you to a page with some information about the website. Go over this information with the user, explaining that the information is provided to give them basic information about each site we provide as Web Links.

Click on the URL link (which is the address of the site) to take you to the American Cancer Society site. Explain to the user that they have now exited the CHESS site and are now at the American Cancer Society website. Show them how they can return to CHESS by using the BACK button on the browser. Note, in this case you can not return to CHESS, so you will have to either hit the home key and re-log in, or go to the History and return to CHESS that way. Once you get back to CHESS, return to the Services page by having the user click on Services at the top left of the screen.

d. Ask an Expert

This service allows the user to ask questions anonymously (the user is only identified by her code name) to an expert in the area of breast cancer. Questions can deal with issues such as medical, social, financial, spiritual, emotional... Explain to the user that the Expert works with a group of experts in various fields who can assist in answering questions that she may not be trained to answer. Questions are answered within 2 business days.

Have the user click on "Ask an Expert". Then have her click on "Ask the Expert A Question." A blank box will appear on the screen. Have her type "Who Are The Experts?" Remember she is using your codename so she will not get an answer if she types a question she is really interested in.

Next, have her click on "Read Answers to Your Questions." The Welcome Message from the Expert should show up. Have her read the welcome message. Explain that if there are no new messages, it means the expert hasn't answered it yet. If she does not get a response from the Expert within 2 business days she should call the Study Coordinator so she can check to see that there are no computer problems.

During this time, you should also show the user the Open Expert messages. Explain that when the Expert gets a message from a woman that she feels is applicable to the entire group, she will take out all identifying information and will put it in the Open Expert section so everyone can read it. Show her how to use the keywords to look in the Open Expert section for topics she is interested in. To return to the Services page, click the button on the upper left of the screen.

e. Discussion Group

Explain that Discussion Group is a service that allows the user to talk confidentially and anonymously to other people who have access to the CHESS computer. There are several discussion groups which the user can take part in by reading and/or writing messages. The discussion groups are anonymous. No one knows the user's real name, they only know each other's code names unless a user reveals their real name.

CHESS offers two types of Discussion Groups, World Groups and Local Groups. The World Groups can be used by anyone who has access to CHESS. Patients in specific local areas, as well as in different research studies will use Local Groups. Local groups are limited to approximately 40 users. The installer should set up which Local and World Groups that the user can be a part of before beginning the training.

If a family member wants to use the CHESS system, they need to get a codename and password from the site coordinator. They are more than welcome to use the system once they have these things.

Sending messages in Discussion Group works the same way as Ask an Expert. To read through messages, click on "Read New Messages." Any new messages will automatically be loaded into the computer (this might take a few minutes). A list of all the messages will then appear on the screen. The newest messages will be on the bottom of the list. Click on the message you want to view. The message will appear. To reply to a message click on the "Write" button at the top or bottom of the screen. A blank box will appear on the screen (just like in the Ask an Expert Service). Show how to write a message but do not send the message, simply erase the message.

You should also explain the Discussion Group Archives and Introductions at this time. Tell the user that the Archives work like the Open Expert questions, except the Discussion Group facilitators do the work that the Expert does for Ask the Expert by taking the identifying information out of the answers if they want to post them in the Archives. The Archives are also linked by keywords.

Introductions allow users to fill in some general information about themselves so others get a better sense of who they are. They can fill in as little or as much as they wish. Users will need to open a message in order to access Introductions. If the person who wrote the message also has an Introduction, the Introduction button will appear in the list of buttons on the message.

Ask the study participant to send a message in Open Discussion within the next couple of days, even if the message simply says this is a test. Also encourage them to fill out the Introduction. That way the Discussion Group Facilitator (a CHESS Staff Person) will know that the computer is working fine. Click on the Services button to return to the Services page.

f. Decisions and Planning Guides

Briefly go through Decisions, Decisions with the woman. Decisions, Decisions is broken up into two categories: Decision Workbook and Learning From Others. Begin by going through Decision Workbook with the user.

There are 3 decision tools in the Decision Workbook available for women with breast cancer. They are:

- Choosing a Surgery
- Chemotherapy
- Clinical Trials

The program contains step by step instructions of what to do. Each step describes the various options and discusses the concerns for each option. The users are asked to consider each option against the concerns, which other

women with breast cancer felt were important. They may also want to type in their own options and concerns. At the end they will be taken to a summary screen which combines all the options with the concerns they felt were important.

Learning From Others is also a decision making tool. It is made up of various women telling their personal experiences with different aspects of their breast cancer experience. The women tell their stories using video and audio so the users can both see and hear them. Be sure to show the women how to use the video capabilities.

g. Health Tracking

In Health Tracking, the participant can choose which health issues she wants to keep track of over time.

Click on Health Tracking so she can see the list of items she can track. Choose from the three lists (Physical Health, Social/Emotional or Health Risks) several items to track.

Click Move On at the bottom of the screen. This will take her to the beginning of the questions the program will ask about each item she has chosen to track. Go through a couple of questions and then tell the woman that she can go through it on her own at a later time.

Click on Services at the top left of the page to get back to the Services page.

Briefly touch on the rest of the services verbally with the woman as you finish up the explanation of CHESS. Remind her of the information in Getting Started which will go over each of the services and how they can be of use to her.

4. TRAINING FOR THOSE RECEIVING INTERNET ONLY

To begin training, click on the Internet browser icon on the desktop. The Gateway Home Page will come up as the Home Page for the browser. To begin:

- a. **Explain** the navigation functions of the browser:
 - **Back/Forward Button**
The BACK and FORWARD buttons are located on the browser toolbar at the left hand side of the screen. The BACK button allows the user to jump back to the previous screen you were viewing. The FORWARD button allows them to move forward in the same way.
 - **Scroll Bar**
Show the user how to move the screen up or down by either clicking on the bar with the left hand mouse button and dragging the mouse up or down or by using the arrows at the top or bottom of the screen.
 - **Home**
Explain to the user that this will always bring them back to whatever they have set as their homepage.
- b. **Highlight** the fact that when the cursor moves over a link, it changes from an arrow to a hand. This will help the user find links when they are in the form of pictures or other graphics.
- c. **Show** the user the way that a hyperlink changes color when they have already visited it.
- d. **Show** the user how to use the mouse and click into a search box in order to begin typing the words for the search.
- e. The home page will be set to Alta Vista (www.altavista.com). To change the home page go to View. Choose Internet Options. Type in www.altavista.com
 - a. **Demonstrate** how to use the search engine Alta Vista (www.altavista.com). Use the help section provided on the page to show the user different ways to search and then try searching for something they are interested in. A suggestion would be to have them search for "dogs", and then, to narrow the search, search for "police dogs." This will give them an idea of how many entries will can come up for a general topic, as well as how to narrow their search topic.

At the end of the training, highlight the information you will be leaving with them making sure they know they can refer to it if they have any questions, as well as for suggestions of good websites to visit.

5. TURNING OFF THE COMPUTER

Explain that when the user is finished using CHESS and wants to turn it off, she should first click the Exit button on the tool bar. This will return her to the "Welcome to CHESS" screen.

The user should then double click on the two attached computers down in the bottom right hand side of the screen. A box will appear called "Connected to CHESS Internet." She should click "Disconnect" in order to disconnect her computer from the Internet.

To turn off the computer she should click on the "Start" button on the lower left-hand corner of the screen. Then she should click once on "Shut Down." Another message will pop up and she should choose "Yes" to shut down the computer.

At this point have the user start up the computer and log in using their own code name and password just to be sure that they know how to start it up. Once they get logged on, have them exit and turn off the computer.

6. OTHER INFORMATION

- a.** Ask the woman you are showing the computer to if she has any further questions.
- b.** Be sure that your name and number is written down on the instruction sheet in the folder. Reassure her that she can call you if she has any questions, needs any help, or is having trouble.
- c.** Tell them that you will give them a call in about a week in order to make sure everything is going okay.
- d.** If they have received CHES, reiterate that you would like them to write a note in the open discussion group within the next few days in order make sure that their computer is working properly. They can write a real message or simply write, "this is a test."
- e.** Thank them for their time!

Appendix # 8

Consent Form

University of Wisconsin, Comprehensive Cancer Center

Consent Form

Study of: Effects of Alternative Decision Support Technologies on Breast Cancer Patients
Knowledge of Options and Satisfaction with Treatment Decisions

Participating Institutions: 1) Center for Health Systems Research and Analysis

College of Engineering
University of Wisconsin - Madison
610 Walnut Street - 1119 WARF Building
Madison, Wisconsin 53705

2) Mayo Clinic, Rochester, Minnesota

3) Medical College of Wisconsin

Phone: 608-263-4882

Investigators: Professors David H. Gustafson and Francois Sainfort

Invitation

You are invited to participate in a research project to study different ways of providing information and support to help women with breast cancer make treatment decisions. The study is being funded by the Department of Defense. You are being invited because you have been diagnosed with breast cancer and are still in the process of making surgery or other treatment decisions. Participation is entirely voluntary. If you choose not to participate in this study, it will not in any way affect your care or treatment by the hospital or clinic, your doctor, nurse or counselor, or your participation with any other services or programs. If you decide to participate, you will be one of about 400 women from various parts of Wisconsin and Minnesota (and surrounding areas) involved in the study.

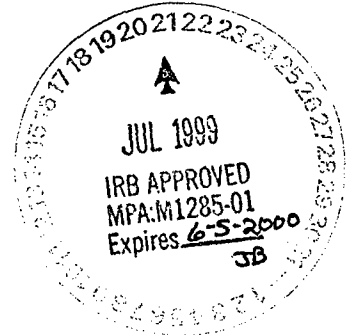
Purpose

The purpose of this research is to evaluate what is the most useful way to provide information and support to help women with breast cancer make difficult decisions about their treatment. We also hope to learn how the systems may be helpful and for what kind of people. The 3 different systems which we will be studying in this research are described as follows:

The CHESS system:

The CHESS system is a computer program which provides the following:

- 1) up-to-date medical, social and legal information about breast cancer (such as information on symptoms and treatments);
- 2) help in making decisions you may be facing (like whether to have a lumpectomy or mastectomy);
- 3) advice on where you can go for help and on how you can make the best use of health and human services;
- 4) a way to talk with physicians, counselors and other people with breast cancer without ever needing to share your name or see them in person. This is done by sending anonymous messages through the CHESS network of electronically linked computers.



REVISED
JUNE 7, 1999

The Internet System:

The Internet is a series of electronically linked computers. The Internet can:

- 1) provide up-to-date medical and other information about breast cancer (such as information on symptoms and treatments);
- 2) provide a way to enter chat groups made up of others with an interest in breast cancer where you can discuss breast cancer issues, get information, ask questions, and receive answers.

The Video System:

The video system has two video tapes of women with breast cancer discussing how they made treatment decisions. In the first tape women who chose lumpectomies and those who chose mastectomies explain how they made their choices and why. In the second tape, women discuss how they decided about chemotherapy and what their choices involved.

What does participation involve?

You will be randomly assigned (a selection process similar to flipping a coin) to a control group or to one of the 3 experimental groups (the CHESS, Internet, or Video systems). Because assignment is random, we cannot guarantee which of the four groups you will be assigned to.

- 1) If you are assigned to the group receiving CHESS, the program can either be installed on your own computer, or we will loan you a computer to use in your home for five months. We will also train you in how to use CHESS.
- 2) If you are assigned to the group receiving the Internet, you will be given free access to the Internet on your own computer or on a computer we loan you if you do not have one. You will also receive training in how to search the Net for breast cancer related issues.
- 3) If you are assigned to the group receiving the videos, you will have a chance to view the tapes at two of your regular clinic visits. (Should you want to see the videos again, the clinic will arrange for this as well)
- 4) If you are assigned to the control group, you will be given a choice of one of three books: *Dr. Susan Love's Breast Book*, *Breast Cancer, Let Me Check my Schedule* or *Celebrating Life, African American Women Speak Out About Breast Cancer*. Dr Love's book is a comprehensive and up-to-date book was written by a physician who specializes in breast cancer. She covers many of the questions and issues for women with breast cancer. The other two books include stories of other women who have had breast cancer and how they dealt with it.

Regardless of which group you are assigned to, you will be asked to complete two types of surveys during the study. *The first* is a longer written survey which we will ask you to complete before you start the study, and then at two months, four months and at nine months after the study begins. These surveys will ask you questions about your health, treatment decisions and quality of life. The surveys take about 30 minutes to complete. You will be paid \$15 for completing each of the 4 surveys. *The second* is a short, one page questionnaire which asks you questions about your treatment decisions. We will ask you to complete these short questionnaires at 2, 4, and 6 weeks after you start the study. You will be paid \$5.00 for completing each of these questionnaires, or \$15.00 if you complete all 5 of them. The total amount of money you will make for completing the 4 longer surveys and 3 shorter questionnaires is \$75.00. Additionally, your medical records will be reviewed to determine the types of treatments you received.

If you are assigned to the CHESS system or the Internet, the computer will automatically collect data on how, how often and for how long you use each of the various parts of CHESS. This data will be used to determine which parts of CHESS are the most useful and valuable.

Data from the control and experimental groups will be compared to see if the different technologies have different effects on their users.

How will we protect your confidentiality?

Ensuring your confidentiality is very important to us. Only the clinic staff and site coordinator will have your name. Your name and any identifying information will be removed from any data collected, and it will be labeled with an anonymous code number before it is passed on to the rest of the research team. No one who knows you or has access to your name will see your completed surveys.

Representatives from the U.S. Army Medical Research and Materiel Command (and, where applicable, the Food and Drug Administration, and the U.S. Army Medical Department Center and School) may inspect the records of the research in their duty to protect human subjects in research which they fund.

What are the costs of participation?

There will be no cost to you, whether you are in the control or experimental groups. If you are in one of the groups that are using a computer for five months, all access is via an 800 number, with no charge to you. There will also be an 800 number for technical support if you need it. If you do not have a phone in your home, the study will pay for monthly phone charges while you have the computer. However, no long distance phone calls will be paid for by the study.

Any damage to the computer, equipment failure, or theft of the computer system is the responsibility of the study designers, **not the participant**. In the case of theft, you must file a police report.

What are the benefits of participation?

If you are assigned to a group receiving a computer we believe that you will benefit by being able to get information, advice, and support at your convenience in your home without ever having to let people know who you are. You will be able to read the latest information on new treatments and progress in breast cancer research. If you are assigned to the group receiving the video, you will also benefit by having a fairly short and easy to understand summary of factors important to you in making treatment decisions. If you are in the control group, you will not receive any direct benefit. However, when the project is done, your contribution will help us decide if any of the systems benefits patients.

All subjects who complete the study, experimental and control, will be paid \$15 for completing each of the three longer surveys, and \$55 for completing all 3 short questionnaires, for a total of \$75.

What are the risks of participation?

There are risks to this project like most things in life, but we believe the risks to be small. They include the following:

- 1) The questionnaires may provoke anxiety. You may refuse to answer any/all questions which cause you discomfort.
- 2) The CHESS program could give you wrong information. However, a panel of experts in breast cancer reviews all information before it goes into the program.
- 3) You could receive wrong information from the Internet.
- 4) The Internet Chat groups may provoke anxiety since anyone may join and send any type of message they want. Although other members of the groups often try to control people who send unpleasant or inaccurate messages.
- 5) It is also possible if you leave your code name and code number written down where someone can see it, that they could use this information to read your messages or send new ones.
- 6) It is also possible that, if you are assigned to the CHESS experimental group or the Internet group, you will develop an attachment to having the CHESS system in your home, and that you will feel some regret and/or loss when the system is removed. The system will, however, remain available to you in community sites, so you can maintain the connection and support.

Will compensation be made for any injury resulting from this research?

For more information on the rights of research subjects, you may contact the hospital Patient Rights Representative at (608) 263-8009.

If you change your mind...

You are free to withdraw from this study at any time. A decision to withdraw will have no effect on any treatment by your hospital, doctor or counselor, or your participation with any other services or programs.

Before you sign this form, please ask any questions on any aspect of this study that is unclear to you. If you wish to speak to Dave Gustafson, the principal investigator of this project, please call (608) 263-4882 and leave a time, location or number where you can be reached. All contact will be completely confidential. We will meet with you or call you as you wish. You may take as much time as you want to think this over.

AUTHORIZATION: I, _____, have read the above and choose to participate in the research project described above. I agree to allow the clinic staff to send relevant information from my medical records to the research staff. My signature also indicates that I have received a copy of this consent form.

Signature

Date

Signature of Principal Investigator
or Person Obtaining Consent

Telephone

ROUTING AND TRANSMITTAL SLIP

Date

6/12/01

TO: (Name, office symbol, room number,
building, Agency/Post)

Initials

Date

1. DTIC - OCA

2.

3.

4.

5.

<input checked="" type="checkbox"/> Action	File	Note and Return
Approval	For Clearance	Per Conversation
As Requested	For Correction	Prepare Reply
Circulate	For Your Information	See Me
Comment	Investigate	Signature
Coordination	Justify	

REMARKS AD# ADA384098

I found this record at DTIC that has an error. The Contract number should be DAMD17-98-1-8259 versus DAMD17-98-1-9259. Please make correction. Thank you.

DO NOT use this form as a RECORD of approvals, concurrences, disposals, clearances, and similar actions

FROM: (Name, org. symbol, Agency/Post)

Room No.—Bldg.

Christine Cheli
MEMR-RMI-S

Phone No.

301-619-7327

5041-102

☆ U.S. G.P.O. 1992 312-070/40022

OPTIONAL FORM 41 (Rev. 7-76)

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FPMR (41 CFR) 101-11.206



Record Retrieved

[HOME](#) [SEARCH](#) [INFO](#) [MAP](#) [?](#)

Document Title : Effects of Alternative Decision Support Technologies on Breast Cancer Patients' Knowledge of Options and Satisfaction With Treatment Decisions

[<-- Previous Hit](#)[Next Hit -->](#)

(This is hit 2 of 4.)

AD Number: ADA384098

Subject Categories: HUMANITIES AND HISTORY ANATOMY AND PHYSIOLOGY MEDICINE AND MEDICAL RESEARCH

Corporate Author: WISCONSIN UNIV-MADISON

Title: Effects of Alternative Decision Support Technologies on **Breast** Cancer Patients' Knowledge of Options and Satisfaction With Treatment Decisions

Descriptive Note: Annual rept. 1 Jul 1998-30 Jun 1999

Personal Authors: **Gustafson**, David H.

Report Date: JUL 1999

Pages: 101 PAGES

Contract Number: DAMD17-98-1-9259

Monitor Acronym: XA

Monitor Series: USAMRMC

Descriptors: *COMPUTER APPLICATIONS, *LIVING STANDARDS, *DECISION SUPPORT SYSTEMS, ***BREAST** CANCER, CONTROL, DECISION MAKING, HEALTH, QUALITY, SURVEYS, INSTRUMENTATION, PATIENTS, WOMEN.

Abstract: The objectives of the research are to (1) develop an innovative computer-based decision support system (cDSS) that will enable women with **breast** cancer to integrate the information available to them, understand diagnoses, treatment options, and risks associated with treatment options, construct and structure their preferences, and make important health decisions; and (2) assess the impact of the new cDSS by making it available to women newly diagnosed with **breast** cancer and comparing it with two other existing technologies and a control group in a carefully designed experiment. The assessment of the impact will be made in terms of understanding of diagnoses, treatment options, and risks associated with treatment options, satisfaction with decisions made, amount of involvement in decision, compliance with decision, change in health status and change in quality of life. This report details the progress made in the development of the CDSS as well as overall enhancements to the CHES system. The study design and protocol are described as well as the survey instruments developed for this study. Recruitment is just beginning for this study, therefore no results will be reported at this time.

Limitation Code: APPROVED FOR PUBLIC RELEASE

Source Code: 380100

Citation Creation Date: 06 DEC 2000

Should be 98-1-8259

Hard Copy Cost